
The State of 21st Century Financial Incentives for Americans with Disabilities



National Council on Disability
August 11, 2008

National Council on Disability
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The State of 21st Century Financial Incentives for Americans with Disabilities

This report is also available in alternative formats and on the National Council on Disability (NCD) Web site (www.ncd.gov).

Publication date: August 11, 2008

202-272-2004 Voice
202-272-2074 TTY
202-272-2022 Fax

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National Council on Disability

An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

Letter of Transmittal

August 11, 2008

The President
The White House
Washington, DC 20500

Dear Mr. President:

On behalf of the National Council on Disability (NCD), I am pleased to submit a report titled *The State of 21st Century Financial Incentives for Americans with Disabilities*. We believe that this groundbreaking document provides a road map for equality of economic rights for people of all abilities, regardless of race or socioeconomic background.

This NCD report defines or describes financial incentives affecting people with disabilities and presents research findings in key areas of people's lives, such as education and health care. It also describes selected state-level innovations affecting asset development and wealth accumulation. In addition, the report suggests several strategies for securing meaningful employment, career advancement, and benefits needed for daily living and accommodations.

The State of 21st Century Financial Incentives for Americans with Disabilities recognizes that the potential for Americans with disabilities to become full citizens cannot and will not be realized without a redesign of public policy. To that end, this report offers recommendations that can increase opportunities for people with disabilities to become fully involved in the economic mainstream of American society.

We thank you for your leadership in promoting the full participation of people with disabilities through your New Freedom Initiative (NFI). The NFI programs have proved to be comprehensive and effective in addressing challenges faced by people with disabilities in all areas of society. NCD believes that many ideas in this report will help achieve the goals of the NFI, and our Council stands prepared to work with you and the Office of Domestic Policy in the planning and implementation of cooperative actions on these matters.

Sincerely,

John R. Vaughn
Chairperson

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

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Acknowledgments

The National Council on Disability thanks the staff and subcontract team of the National Disability Institute (NDI) of the National Cooperative Bank Development Cooperation (NCBDC) for conducting the research for this report. They include principal investigators Steve Mendelssohn, J.D., and Johnette T. Hartnett, Ed.D. (NDI Director of Research and Strategic Planning), along with NDI Director Michael Morris, J.D., who contributed research, and Carol Harvey, Ph.D., who contributed economic analyses.

NCD also wishes to acknowledge the contributions of study advisors contacted during the early phases of work, including Charlie Hammerman, John Hetterick, Elizabeth Jennings, Tobey Partch-Davies, and Robert Zdenek.

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Executive Summary

For over half a million people with disabilities, the specific reason they never leave home is that they cannot get the transportation they need;¹ the current federal regulations force adults with significant disabilities to remain in a poverty state.²

Background

Limited access to money is one of the most serious problems facing Americans with disabilities, according to a recent National Organization on Disability/Harris survey.³ The Federal Government spends large amounts on behalf of people with disabilities in terms of health care, education, vocational rehabilitation (VR), transportation, housing, and in other areas, whether sources are direct, indirect, or community based (i.e., through specialized services, resources, or environmental access). Yet, the knowledge base is small regarding the extent, costs, utilization, or impact of these incentives, financial or otherwise, on the everyday lives of people with disabilities.

As disability policy stands today, a child with significant disabilities born in the United States in 2007 has little chance of gaining access to assets and escaping poverty, despite advances in health care and technology. In part, a major reason for this conclusion is the all-or-nothing dichotomy of public policy that continues to view disability as the inability to work and that provides needed public assistance only if one remains poor and completely dependent on government help. More than 30 years after the creation of the federal mandate for a free, appropriate public education for children and youth with disabilities, each new generation of parents has higher expectations. Parents envision their son or daughter with a disability having a quality of life as an adult anchored by job satisfaction, independent living, and the benefits of full participation in the economic mainstream. This National Council on Disability (NCD) report, *The State of 21st Century Financial Incentives for Americans with Disabilities*, recognizes challenges to meeting such expectations. Without a redesign of public policy, the potential for Americans with disabilities to become full citizens with the same access to the economic mainstream as Americans without disabilities cannot and will not become

a reality. The redesign must create policy that consistently supports individual objectives to advance self-sufficiency and economic independence. This NCD research is the third in a series (two earlier reports were on Social Security issues⁴ and employment matters⁵) building upon prior NCD work on livable communities. This report is part of an effort, under the umbrella of inclusive livable communities, to guide future policy and practice to advance choice, full community participation, and economic independence for people with disabilities.

Research Framework

This report introduces a new vocabulary as a way to define financial incentives, track their major outcome and impact, and apply this methodology to the study of a number of key incentives. It also provides research findings from a review of the literature in six selected domains: education, employment, transportation, health care and long-term services and supports, income maintenance and asset development, and housing. In addition, this report analyzes research on promising state innovations and introduces a new framework based on four case studies presented with a cost-benefit analysis. The report comprises five chapters.

Chapter 1 defines the concept of financial incentives for the purpose of this study as an intended benefit conferred by Federal Government programs that provide social transfers, usually of cash or in-kind services, designed to change behavior, increase cash flow, supplement services, and support—but rarely enhance or create—assets. This definition differs from the traditional understanding of financial incentives, which implies a benefit intended to enhance profit.

Built upon the aforementioned background information, chapter 1 introduces a topology that draws the strands of policy and experience more tightly together to parlay what was known about the six selected domains and other spheres of public policy into a coherent whole. The proposed topology divides disability-related financial incentives into three broad categories: (1) direct funds, which are provided directly to individuals with a disability; (2) indirect funds, which are provided to third parties for use in connection with

or on behalf of people with disabilities; and (3) community-based funds, which are used for developing various kinds of infrastructure and resources that have a specific purpose or significant effect on the lives of people with disabilities.

Chapter 2 presents a review of the literature conducted and condensed into major findings in the six life domains—education, employment, transportation, health care and long-term services and supports, income maintenance and asset development, and housing. Ten years ago, NCD also reported data like the 17 key findings in this chapter.⁶ The findings have two purposes: to describe barriers, utilization, impact, and outcomes of financial incentives; and to add fresh insight and propose a framework for revising federal programs incorporating social transfer benefits (such as increased cash flow, supplemental services, and supports) that affect the lives of people with disabilities.

Chapter 3 provides the results from research on promising state innovations (direct, indirect, or community based) in Louisiana, Missouri, Wisconsin, Maryland, Kentucky, and Washington. The selection of each program was based on potential for state- or federal-level replication, diverse strategies, and potential to affect people with disabilities. Each selected program addressed a different element of the challenges to facilitate a more advanced social and economic status for individuals with disabilities and their families. Each selected state has adopted policy that may exist in other states but has program elements that are unique in terms of public and private participation and the leveraging of resources to compound the benefits to the individual and family, the community, and the state.

Chapter 4 sets forth a conceptual framework based on the research findings from the first three chapters, a direction for making changes and providing supports to improve the daily living and economic status of people with disabilities. Fundamental to development of the conceptual framework used in this study is a set of financial incentive principles linked to four proposed core strategies for action. The principles are seeing financial incentives as a tool linked to Americans with Disabilities Act (ADA) goals, making choices available to all people with disabilities, aiming for full community

participation, and striving toward universal impact that can boost involvement in livable communities for all citizens. Grounded in the identified principles, the conceptual framework, called Policies Optimizing Workers' Economic Reach (POWER), is a combination of strategies that modify existing policies and enhance direct, indirect, and community-based incentives as a comprehensive blueprint for change. The POWER strategies propose modification to federal entitlement policy, modification to tax policy, enhancement of direct asset-building options, and enhancement of indirect, community-based, and employer incentives, including new and expanded tax deductions. The POWER strategies in chapter 4 involve individual behavioral and Federal Government-level changes that also will affect the major life domains by encouraging work, income preservation, asset building, and awareness raising related to improved access to health care, transportation, continuing education, and affordable and accessible housing, including home ownership.

Finally, chapter 5 recapitulates the key findings pertaining to financial incentives and the NCD core recommendations for action at the federal level. The findings and recommendations are as follows.

Summary of NCD's Key Findings on Financial Incentives

1. Financial incentives are complex and need explanations pertaining to definition and type.

There is no simple definition of financial incentives. While some operational definitions might involve disability-based, case, in-kind, or other funding streams as categories of financial incentives, this report uses three overarching categories—direct, indirect, and community based—according to the topology developed for this research. Efforts to gain an understanding of these variations and to account for as many of them as possible will contribute to making this research meaningful.

2. Financial incentives are underutilized.

Financial incentives in tax and social policy are multifaceted, used in limited fashion, and not well communicated to the public. Examples include limited use of a true asset-building and tax-filing opportunity for employed recipients of public benefits and a tax deduction for individuals who itemize income tax returns.

3. Individuals with and without disabilities are denied the opportunity for savings and asset growth because of the means testing required to remain eligible for many public benefits.

Well-intentioned public programs sometimes reflect disconnections that reduce their effectiveness and put the programs at cross-purposes. The disconnections also render a negative impact likely. For example, means-tested eligibility for public benefits entitlements (Social Security, Medicaid) denies many individuals with disabilities the opportunity to preserve income, save, and build assets.

4. Low-income wage earners do not benefit from many federal tax provisions that promote savings and asset development.

Financial incentives in tax policy that promote asset building are out of reach to low-income wage earners who do not itemize.

5. Direct, indirect, and community-based financial incentives have an important impact on people with disabilities and their families.

Financial incentives across the major life domains (e.g., education, employment, transportation, health care and long-term services and supports, income maintenance and asset development, and housing) affect people. The impact can be direct, indirect, or through community-based entities.

6. There are no one-size-fits-all financial incentives strategies.

Americans with disabilities will benefit from existing and new financial incentives strategies only through targeted and customized outreach that communicates

information, training, and technical assistance in formats that are accessible, understandable, and relevant for all ranges of ability.

7. Financial incentives funding strategies are interrelated.

None of the financial incentives funding strategies studied for this report operates in isolation from the others. One cannot understand housing patterns in the United States unless one understands the tax code, the mortgage industry, and the funding for automobiles versus mass transit. Similarly, one cannot understand the economic status of Americans generally, and of people with disabilities in particular, without reference to the educational system of the United States. No single financial incentive directly or indirectly can produce a better economic future for individuals with disabilities. Many incentives overlap in their goals and together offer a combined and cumulative response to the challenges of poverty for Americans with and without disabilities.

8. Opportunities that encourage and support savings and asset acquisition are limited and need to be expanded for people with low incomes who have disabilities.

A meaningful definition of assets in the modern world must go beyond tangible possessions such as bank accounts, investments, and real estate. The definition also must include resources such as education and health, as well as networked connections such as access to expertise and influence.

The realities of cash flow in the sense of income stream, on the one hand, and assets in the sense of tangible and intangible goods, resources, and other types of assets, on the other hand, are very different things. Disability-related programs, ranging from entry-level employment to cash payments in lieu of employment, have been predicated on a belief in cash flow/income stream. By contrast, most tax-based policy is predicated on cash payments in lieu of employment, in that the policy intentions and effect are to increase the size and leverage value of existing assets, particularly capital assets, rather than to encourage initial asset acquisition.

9. Disability remains an all-or-nothing proposition based on eligibility determination and disability definition.

In public policy, as articulated in the definitions and rules governing almost every law and program, disability is an all-or-nothing proposition. Certainly, this is clearest in the financial support programs. However, even under laws like the Americans with Disabilities Act (ADA), which adopted an enlightened attitude about the ultimate social meaning of disability, the notion of disability has been converted into a largely jurisdictional issue. If a person is determined eligible for public benefits based on a particular definition of disability, then he or she receives benefits A and B. If that person is determined ineligible for public benefits based on a particular definition of disability, then he or she does not receive benefits A and B. Accordingly, under most program models, the existence of disability is correlated with need—need for income support, need for services, need for exemption from otherwise applicable requirements, or need for supervision and control.

10. Several financial incentives need modification to provide parity for people with disabilities.

Some financial incentives incorporate a universal approach and offer benefit to a large class of individuals with and without disabilities. Some financial incentives require modification to provide parity for people with disabilities comparable to their peers without disabilities. Comparable opportunities should be based on consideration of the extra gateway costs needed to level the playing field for a person with a disability because of extra health care costs, assistive technology needs, or other services.

11. A consensus model is unavailable for evaluating the impact of financial incentives.

There are no adequate or consensus models for evaluating the impact of most financial incentives. Even when researchers limit their inquiry to the expenditures and programs that have people with disabilities as their conscious, intended, and sole focus, the absence of suitable baseline data compounds the lack of evaluative criteria. For a variety of reasons, including the small size of cohorts and the lack of comparability in

the life circumstances of individuals with disabilities, standard research methodologies are insufficient, and observational research fails to overcome the ideological fault lines that run through disability policy.

12. Gateway costs of living with a disability are more expensive than costs of living without a disability.

Function for function (e.g., getting back and forth to work, obtaining education, and giving informed consent to a medical procedure), living with a disability costs individuals and families more than living without one. This is one reason that disability costs must be factored into generic financial incentives in order to portray equal value for people with and without disabilities. The gateway costs of living with a disability are unique, often high, and rarely taken into account in the design of public programs or the federal tax code.

13. Disability programs are weighted heavily toward the use of resources for determination of status and assessment of eligibility.

Most federal disability programs are weighted heavily and unduly toward the determination of status and the assessment of eligibility. Most ADA court decisions involve the threshold question of whether the individual has a disability. From the huge investment historically made by vocational rehabilitation in determining eligibility and need for services to the role of objective test dividing lines in determining levels of intellectual disability (often to the detriment of resources for providing the necessary services), programs are concerned as much with ferreting out improper benefit as with helping people who could benefit.

14. The conversion of federal financial disincentives to incentives is possible.

The operation of needs-based program limits across a broad range of federal programs regarding what beneficiaries can receive creates a major disincentive to work, entrepreneurship, or other asset-accumulation activities. This report proposes that, through the development of the Policies Optimizing Workers' Economic Reach

(POWER) framework, needs-based programs could be converted experimentally from disincentives to incentives that help people gain employment and self-sufficiency.

15. Public accounting practices, especially the practices related to federal savings across programs and services, need review.

Existing public accounting practices do not readily permit the computation of projected long-term savings into federal budgeting and appropriations decisions that cut across program authorities. Strictly speaking, the Congressional Budget Office (CBO) legally would not be permitted to take into account the lifetime savings to the Supplemental Security Income (SSI) Program envisioned by the POWER framework in “scoring” the program, which cuts across multiple funding authorities.

16. Definite cost benefits are found when the framework and strategies introduced in this report are applied to three of the case studies presented.

Estimates of disability and health coverage benefits and tax revenue associated with the POWER framework that allow for changes in the treatment of disability benefits and other financial incentives demonstrate positive cost-benefits over total lifetime earnings.

17. Cost benefits for Case Study 4 are unknown because scientifically reviewed, methodologically valid studies for this purpose are lacking.

The necessary data were unavailable to support policies and programmatic proposals that attempt to address barriers to employment and quality of life for people with disabilities.

For the Federal Government to invigorate programs and policies with financial incentives that tap into the potential of people with disabilities, it is necessary to assess the economic impacts and measure the behavioral response to policies that seek to influence individual behavior and decisions. Methodologically sound cost-benefit analyses in the social policy arena require significant time and resources to conduct. Observing the complete impact can take years. Research and implementation efforts used to assess cost-benefits in the arena of public policy encounter a number of

challenges at the federal level. The findings of this report also underscore the need for an overhaul of federally funded financial incentives in ways that modify programs and expand benefits for people with disabilities. Such is the intent of the POWER framework. Indeed, the unveiling and effective implementation of the framework also can unleash literal power yet unseen as a 21st century movement supporting more people with disabilities than in the past—lifting people from the roles of poverty to the ranks of empowerment.

Summary of NCD’s Major Public Policy Recommendations on Financial Incentives

Disability and its role in the mainstream economy, despite the efforts of ADA since 1990, still are not considered a “natural part of the human experience.” The potential for individuals with disabilities to be integrated fully into the workforce and thus into the formal U.S. economy is not understood fully by policymakers or private sector business. This report, *The State of 21st Century Financial Incentives for Americans with Disabilities*, is part of the evolutionary journey of disability policy in the United States and provides a road map for equality of economic rights for people of all abilities regardless of race or socioeconomic background. The following recommendations provide a new frontier for the next generation of Americans with disabilities—allowing them to participate fully in the economy.

Recommendation 1: NCD recommends that the Administration create a federal interagency workgroup on financial incentives for people with disabilities and their families; develop an Executive order calling for all agencies to identify policy barriers; and create a time-limited body to facilitate a consistent, coordinated, comprehensive, and consumer-friendly approach to advance opportunities for full community participation and economic self-sufficiency.

Implementation Lead: The President and Cabinet members should implement this recommendation. The federal agency lead should be the director of the Office on Disability, Department of Health and Human Services. Other interagency workgroup

members should include the departments of Labor, Housing and Urban Development (HUD), Transportation, Education, and Treasury, the Social Security Administration (SSA), and representatives from the Department of Health and Human Services Centers for Medicare and Medicaid Services.

NCD urges the President to issue a new Executive order that charges the full range of federal agencies with identification of policy barriers and facilitation of a consistent, coordinated, comprehensive, and consumer-friendly approach to financial incentives. The intent is to advance full community participation and economic self-sufficiency for people with disabilities and their families through financial incentives, both directly and through third parties in the public and private sectors. The time-limited workgroup (six months) would develop an action plan with recommendations for policy and program changes that would accomplish the following:

- Increase consumer choice
- Encourage income preservation and asset building
- Improve interagency coordination
- Reduce and eliminate policy barriers to improved economic status and community participation
- Provide incentives for private sector support of community access and participation in the economic mainstream
- Adopt universal design principles in housing, transportation, public spaces, and public accommodations
- Reduce the connection between disability and poverty in the continued eligibility for public benefits

The secretary of the U.S. Department of Health and Human Services would request the director of the Office on Disability to chair the workgroup. The final report to the President would include recommendations for policy and program changes not limited to changes to the federal tax code or entitlement authority.

No single agency or policy solution can produce the comprehensive reforms needed to align financial incentives that directly and indirectly will support the range of choices people with disabilities desire to be fully productive, independent, and active participants in the economic mainstream. The workgroup would bring to the table the array of agencies needed to transform policy and practice.

Recommendation 2: NCD recommends that Congress review, introduce, and consider adoption of the POWER framework through changes in federal legislation pertaining to Social Security, Medicaid, savings, asset building, and the relevant aspects of the federal tax code.

Implementation Lead: Through the committee chairperson, the Senate Finance Committee, with its jurisdiction over the federal tax code and entitlement programs, may be the logical starting point for a congressional hearing to clarify the current challenges that force people with disabilities to remain poor in order to access minimal public benefits. Recommended for additional consideration are the House Committee on Ways and Means and the House Committee on Energy and Commerce.

The multiple components of the POWER framework offer the opportunity to advance a consistent agenda for a better economic future for individuals with disabilities and their families.

Recommendation 3: NCD recommends that the Department of Education take appropriate actions to expand the knowledge available about the cost-benefit outcomes of direct and indirect financial incentives and to advance self-sufficiency for people with disabilities. These actions would include the establishment of a new Rehabilitation Research and Training Center (RRTC) on Financial Incentives to Advance Self-Sufficiency charged to increase the sparse knowledge base.

Implementation Lead: NCD recommends for leadership the U.S. Department of Education, with the involvement of the assistant secretary for the Office of Special

Education and Rehabilitative Services and the director for the National Institute on Disability and Rehabilitation Research (NIDRR). NCD recommends collaboration with the assistant secretary for planning and evaluation, Centers for Medicare and Medicaid Services, in the Department of Health and Human Services, and the Social Security Administration.

In collaboration with the agencies identified, NIDRR should establish a new RRTC on Financial Incentives to Advance Self-Sufficiency. The RRTC would develop new methods and measures to help diverse audiences better understand the impact of financial incentives and disincentives across federal agency authorities. These impacts are related to community inclusion and economic participation for individuals with disabilities and their families.

The research findings indicate how little is known about the impact of financial incentives and disincentives for people with disabilities and their families. New knowledge and methodologies designed to clarify the potential impact of direct and indirect incentives on people with disabilities and their families are needed. Multiple federal agencies listed as lead implementers must refine their research priorities to focus much-needed attention on evidence-based financial incentives research. The outcomes can help policymakers at each level of government make informed decisions about resource allocation to support a better economic future on individual and community levels for people with disabilities.

Recommendation 4: NCD recommends that key federal agencies (see below) fund demonstration projects that improve capacity for employer and community use of financial incentives to advance real economic impact. This work should be included in the written plans and annual reports to Congress of each agency.

Implementation Lead: Senior-level leaders with budget authority should account for effective implementation. The collaboration should occur through HUD as it works with the departments of Labor, Commerce, Transportation, Education, and Treasury, and the Internal Revenue Service (IRS).

The research findings of this report document the potential benefits of leveraging employer and community interest to advance self-sufficiency and integration of people with disabilities and their families. NCD recommends using financial incentives to capture employer and housing developer interests that promote positive economic impact at individual and community levels, and providing data where not enough is known about the cost benefit of indirect financial incentives to advance self-sufficiency and economic status of individuals with disabilities.

A series of demonstration projects coordinated among HUD, the departments of Labor, Commerce, Transportation, Education, and Treasury, and the IRS could evaluate the benefits of a set of financial incentives that encourage affordable and accessible housing design. For example, the evaluative research could study Low-Income Housing Tax Credits, job creation with appropriate supports using New Markets Tax Credits, and employer support of the cost of transportation, continuing education, and rent subsidies leading to home ownership based on expanded tax benefits.

These projects would allow for community development of diverse supports with public and private sector collaboration. These supports stimulated by financial incentives would be evaluated for economic impact and cost-benefit, which has not been studied previously. The results will support potential policy change and new approaches to the much-needed improvement of interagency collaboration at federal, state, and local levels.

Recommendation 5: NCD recommends the establishment of a federally funded joint education effort to expand and improve financial education and outreach to children and adults with disabilities across economic levels and types of abilities.

Implementation Lead: At least five federal entities should form a partnership to lead implementation of this recommendation. The initial partnership should include the Federal Deposit Insurance Corporation, IRS, the departments of Labor and Education, and the Social Security Administration.

Research findings documented the importance of developing financial literacy in children and adults with disabilities. Financial incentives require knowledge and basic understanding of money management, credit, and the importance of savings and asset accumulation. The creation of individual budgets, access and use of favorable tax provisions, and the selection of one or more asset-building strategies require expanded emphasis on outreach, education, and training for the targeted population.

The IRS has been expanding its outreach to low-income workers with disabilities to educate and inform eligible individuals about the benefits of the Earned Income Tax Credit. The Federal Deposit Insurance Corporation recently produced Money Smart, a financial education curriculum, in Braille. However more education and increased public awareness are needed. They should include development and dissemination of consumer-friendly information through efforts involving the Social Security Administration (SSA) and the Department of Labor (DOL) and Department of Education. The education should begin in elementary school and continue in multiple venues that support adults with disabilities in order to improve the skills that empower and support income preservation and asset building. The purpose is to advance real economic impact using direct and indirect financial incentives.

SSA and DOL, respectively, should train employees in the SSA-funded Work Incentives Planning and Assistance (WIPA) Program and the DOL-funded Disability Program Navigator Program on how to access the full spectrum of financial incentives that could benefit people with disabilities. Ongoing technical assistance should be available to help support the use of knowledge and to enhance access by people with disabilities.

Outcomes from implementation of these recommendations could turn financial disincentives into incentives. Bold new approaches and directions hold the hope of breaking existing patterns and providing a way to eliminate economic and other disparities between people with disabilities and those without disabilities. This report makes detailed, far-reaching proposals for conducting the necessary demonstrations, as highlighted in the five recommendations above and discussed more specifically in the full report.

Chapter 1: The Topology of Financial Incentives for Americans with Disabilities: A Review of the Current Federal Experience in Providing Direct, Indirect, and Community-based Financial Incentives to Americans with Disabilities

An individual with a disability is three to four times more likely to live in poverty as an individual without a disability.⁷

1.1. Introduction

The federal and state governments and the nonprofit sector spend enormous sums on people with disabilities and in connection with disability-related issues—more than \$300 billion annually. Determining the exact amount of such expenditures is difficult.

To be fully meaningful, an effort for aggregate fiscal or expenditure data collection must accomplish three goals. First, it must create expenditure and outcome categories that are meaningful to the people receiving, spending, or benefiting from the funds, and that resonate with the public's and legislators' understanding of the issues. Second, it must both allow for comparative assessments of investment in various options and permit analysis of the impact of increases or decreases in one area of spending upon costs in other areas. Third, it must allow for the creation of outcome criteria that are measurable and against which difficult value judgments can be made nonpolitically and nonideologically.

Accomplishing these goals is no easy task. Appropriate baseline data do not exist; prospective information-collection procedures are not in place; consensus has yet to form around the definition of expenditure categories that make most sense; outcome measures are still in their infancy; and outcome criteria are subject to innumerable political, economic, and philosophical cross-currents. A building process likely of several years' duration must be put in place before the key questions can be asked and answered, and before evidence-based policy and resource allocation decisions truly can be made.

Current Context

For a number of years, NCD has published groundbreaking studies that assess the status and impact of public policy in major areas of life, such as education, housing, health care, long-term services and supports, employment, and transportation. Taken together, these and other studies present a broad panorama of government efforts, societal conditions, and program strengths and failures. Consistent with a long-established value framework, a review of these studies as they have been published (or updated) provides an unequaled overview of the structure and nature of disability policy, and of the way people with disabilities live their lives in this country.

The strands of policy and experience need to be drawn together more tightly to parlay into a coherent whole what is known about education, housing, health care, long-term services and supports, employment, transportation, and other spheres. A common vocabulary and topology allows assessment of the six areas in combination and also allows us to compare, contrast, and integrate findings effectively, and to study overlaps and interconnections with new flexibility, facility, and confidence. Issues of definition and questions of categorization are certain to arise. Therefore, while extensive details of the topology are available on the NCD Web site (www.ncd.gov), definitions essential to this research report and information about an economic and demographic context are presented below.

Defining Financial Incentives

Broadly, financial incentives are defined as benefits that confer economic well-being and opportunity. *Webster's Unabridged Dictionary* defines an incentive as something that promotes or incites greater productivity.⁸ The economist Levitt describes incentives as "the cornerstone of modern life and that the ability to understand them is the key to solving just about any riddle."⁹ Levitt and Dubner write that incentives come in "three flavors, economic, social and moral," but rarely does an incentive represent all three.¹⁰ The most common definition of a financial incentive is a benefit that is intended to enhance profit. Financial incentives drive the marketplace for pharmaceuticals, insurance companies, health care, and technology industries. The other definition of

financial incentives and the one used in this study is the intended benefit conferred by Federal Government programs that provide social transfers, usually of cash or in-kind services, designed to change behavior, increase cash flow, and supplement services and supports, but that rarely enhance or create assets.

Disincentives also play a large role in understanding financial incentives. An example is the current debate about the development of an AIDS vaccine.¹¹ While the Federal Government and private industry both are investing resources in research for a vaccine, none has been found.¹² The problem probably is not a lack of resources from the public or private sector but a competing “disincentive” created by profit margins already being realized from existing AIDS drugs. Arguably, the profit margins may be too great to leverage the relative profitability of a vaccine, although inevitably a vaccine will be discovered and marketed for profit.

Disincentives are rife in disability policy as well. Selected disability policies are at odds with advancing independence and productivity. A good example of the consequences of conflicting policies is the chronic unemployment experienced by individuals with disabilities. Failure is all but guaranteed when an individual with a disability attempts to work full time while receiving federal benefits. Federal eligibility and program rules do not complement each other across federal disability programs, so the incentives from one federal program turn into disincentives when interfaced with another program. Misdirected policy and funding of programs that promote “work incentives” that are really “disincentives” cannot in truth produce outcomes that include employment. As this review will demonstrate, current disability policy does not have unified goals, measurable program outcomes, and clear funding expectations that are universal across federal agencies and that promote economic independence and self-sufficiency.

Understanding the Incentives of Spending and Tax Entitlements

The United States enters the 21st century ill prepared to finance its current spending and tax entitlements that benefit low-, middle-, and upper-income Americans with and without disabilities.¹³ Federal spending for all entitlements, whether mandatory or

discretionary, whether means-tested or not, for retirements, for safety net programs, and for tax deductions, is rising and unsustainable.¹⁴ Rising costs for health care provided by Medicaid and Medicare are at the center of the problem.¹⁵ Actuaries are reluctant to predict future spending scenarios given the uncertainties of future health care costs that continue to rise yearly at double-digit rates. Even though Medicaid growth rates have slowed in the past few years, Medicaid accounts for 21 percent of total state budgets.¹⁶ The comptroller general of the Government Accountability Office wrote that incremental reform for entitlement spending is no longer good enough to fix the problem.¹⁷

One way to define a problem is to measure it. How a problem is measured is more than a rudimentary process of tallying or counting: it is a conscious act of inclusion or exclusion.

—Deborah Stone, *The Policy Paradox*, 1997, p. 164

Recent research on federal disability programs highlights the costs of more than 200 federal disability programs but is silent about the benefits and impact for 34 million beneficiaries with disabilities.¹⁸ What is known is the Federal Government is spending more than \$245 billion a year for programs dedicated to individuals with disabilities—half of which is for health care programs such as Medicaid and Medicare.¹⁹ Evidence-based research to date is thin and does not correlate the impact and costs with outcomes clearly and consistently across the wide array of federal programs. Without evidence of the impact and outcomes on the lives of individuals with disabilities, researchers and policymakers do not know if too much, too little, or just the right amount is being spent. Congress and the White House have received research that demonstrates the “high risk” and “high costs” of current disability program spending, but have not been given research on the “benefits” and “outcomes” for individuals with disabilities and their families or for American society as a whole. Congress cannot answer these questions fully without cost-benefit research. Federal disability spending from a market perspective could be paying for itself because of the overall “benefit” and “cost savings” it confers. Certainly, life for the one out of five people in the general population (or more than 50 million Americans with disabilities) would look quite different given no federal spending or tax entitlements on their behalf.

While the value of the emerging disability industry from a market perspective is a different question not addressed in this review, it is worth mentioning. Whether growth in the private disability market is correlated to growth in federal disability legislation is unclear. However, the disability market is here to stay and will expand and produce profits as the population ages and prevalence of disabilities rises.

As this review begins, there are two camps of support for federal financial incentives, each with different goals. On the one hand is the support for financial incentives that are intended to enhance and increase wealth through tax deductions, such as pension or health insurance contributions paid by employers. Primarily, these incentives target Americans under age 65.²⁰ On the other hand there is support for financial incentives that are intended to supplement or provide cash or in-kind services to a population of Americans both over and under age 65, with or without disabilities, who often are poor. Unlike the tax incentives, the spending or safety net incentives, given their rising costs and increasing roles, are at the center of much federal agency and congressional concern. There is much discussion about the costs of these incentives but little discussion about what reforms or changes are necessary to ensure sustainable and equitable policy well into the 21st century. This chapter will briefly review definitions of spending and tax entitlements as well as their economic and historical context to clarify their role in this financial incentive research.

For the purpose of this study, financial incentives are defined as the outcome conferred, whether cash or in-kind, on individuals with disabilities, whether positively or negatively impacted by government spending and tax entitlements. Eligibility for federal spending and tax entitlements is broad for both individuals with and without disabilities: One can be a member of a particular group, like a veteran or senior or a homeowner; or one can earn a benefit through payroll deductions such as Social Security pension or Social Security Disability Insurance. Some entitlements, such as Medicaid, are means-tested and require income eligibility tests, versus a program like Medicare whose primary entrance criterion is age.

Some entitlements, such as Social Security and Medicare, are formula based or have dedicated revenue streams attached to them that pay benefits without an annual appropriation by Congress.^{21,22} Historically, this authority was granted to “reduce the uncertainty of the annual funding cycle through which programs traditionally pass.”²³ Other entitlements, such as Medicaid, Supplemental Security Income, welfare, and other safety net programs, require yearly appropriations from Congress to pay benefits in accordance with underlying statutes. The House and Senate budget committees define entitlements as a combination of “any federal outlay that either requires no annual appropriation by Congress or must be appropriated by Congress according to the terms of some underlying statute or program legislation.”²⁴

In addition to the traditional spending entitlements for retirement programs, safety net programs, and health care, there are tax entitlements that confer benefits on individuals through the tax code and allow for special deductions and credits.²⁵ For example, to a homeowner the tax benefit allows deducting mortgage interest; to a builder the tax benefit means receiving tax credits for targeting housing units for individuals with disabilities; to low-income individuals the tax benefit could mean receipt of the Earned Income Tax Credit or participation in a matched savings account; and to an employer the tax benefit could mean tax credits for providing pension and health care contributions to employees.

AARP’s policy research division found that “during times of recession entitlement spending increases as a share of the GDP [gross domestic product] and declines as a share during expansions” and that different categories of entitlements experience different growth patterns.²⁶ In the past 15 years the only spending entitlement that has increased and that is projected to increase as a share of the economy in the next 10 years is health care or Medicare and Medicaid. Retirement and safety net programs (including SSI, food stamps, social services, and unemployment compensation, to name a few) declined by 2.4 percent of the GDP between 1983 and 2001 and are projected to decline by 0.3 percent of the GDP by 2021. Health entitlements (Medicare and

Medicaid) increased by 1.5 percent of GDP for the same time period and are expected to reach 2.5 percent by 2012.²⁷

AARP researchers found that more than 50 percent of spending entitlements, for the population ages 65 and over, go to household units whose annual incomes are below \$30,000.²⁸ On the other hand, 72 percent of tax entitlements (mortgage interest, child tax credit, untaxed Social Security, Earned Income Tax Credit, child care credit, charitable contributions, savings and loan income, property tax, real estate tax, and medical expenses) go to individuals making over \$50,000 and only 22 percent go to people making under \$30,000. The Earned Income Tax Credit is an exception because it is “both a spending entitlement and tax entitlement (because it reduces taxes but also results in cash benefits) and if it were excluded more than 82 percent of the tax benefits would flow to people with incomes above \$50,000.”²⁹ Unlike spending entitlements that benefit mainly individuals over age 65, tax entitlements benefit mainly individuals under age 65.³⁰ If 82 percent of tax benefits go, not surprisingly, to people with income, then it follows that spending programs, to the extent they exist to help the less wealthy, should be equally skewed to the poor and individuals with disabilities.

Understanding Disability Demographics

The world’s population quadrupled in the 20th century and is predicted to grow by 50 percent by the end of the 21st century.³¹ In less than a hundred years, life expectancy in the United States increased 30 years, with the fastest-growing age group now in their eighties. Along with this unprecedented population growth is the fact that the industrialized countries, with the United States in the lead, account for only 20 percent of the world’s population but produce about 80 percent of the gross world product.³² As the industrialized world ages, it is projected that its productivity will decline as it is forced to allocate resources to health care and pensions.³³ A number of trends in the United States will require significant changes in American social and tax policy, such as the reduced number of workers per retiree; reduced fertility rates; the growing challenges of the health care workforce; and the low national savings rate. Add to these changes the increase of diverse racial and ethnic groups, lack of any national long-term services and

supports policy, rising health care costs, growing numbers of underinsured and uninsured Americans, the 25 percent increase in disability since 1990, and the projected doubling in the number of elders over the next decade.³⁴

Poverty

There were 54 million Americans reporting a disability in 2004; over 20 million of those represent families who report having at least one member with a disability.³⁵ Thirteen percent of families report having at least one member with a disability, and 25.7 percent report having two members with a disability.

In 2000, 8.7 million people with disabilities were poor, with 17.6 percent age 5 and older, compared to 10.6 percent for people without disabilities. Twenty-five percent of American children with disabilities (ages 5 to 15) live in poverty compared to 15.7 percent of children without disabilities. Americans with disabilities between the ages of 16 and 64 make up the group with the next largest number of people living in poverty, at 18.8 percent—nearly double the rate for people without disabilities (9.6 percent).³⁶

Data indicate that the number of all children living in poverty has risen since 2000 to 17.3 percent, or 12.5 million. Fifty-seven percent of these children live in families headed by their mother; 33 percent have no family workers; 33 percent live in families with year-round full-time workers; and 26 percent live in families headed by an immigrant. The financial incentives that make up the society safety net for children are mostly direct (needs-based transfers of cash and noncash benefits) and indirect (earnings-based social insurance and tax credits).³⁷

Geography

Disability prevalence³⁸ is higher in the South than in the other three regions of the United States. Two out of every five people in the South—20.9 percent, or 19.2 million people—have a disability, while in the other three regions of the United States one out of every five people has a disability. The West is second, with 10.8 million; the Midwest is third, with 10.5 million; and the Northeast is last, with 9.5 million people with

disabilities. For families, disability prevalence is even higher, with 30.8 percent of families in the South, or 8.1 million, reporting a member with a disability.³⁹

Among states, West Virginia has the highest disability rate, with 24.4 percent, followed closely by Kentucky (23.7 percent), Arkansas (23.6 percent), Mississippi (23.6 percent), and Alabama (23.2 percent). The five states also register higher rates of individual disability measures than the rest of the country in sensory (hearing and vision), physical, and intellectual disabilities.⁴⁰ Virginia, Maryland, and Delaware, on the other hand, register disability rates significantly below the national rate. The highest disability rates were found clustered in the coal-mining areas of Kentucky and West Virginia in 2000.

Employment and Income

Employment favors people without disabilities, with 79.9 percent of working-age men between the ages of 16 and 64 employed compared to 60.1 percent of men with a disability. Working-age women without disabilities also experience higher employment rates of 67.3 percent compared to 51.4 percent for their colleagues with disabilities. The employment rates for family householders with disabilities were 53.3 percent, compared to 80.7 percent of all family householders.⁴¹

Families with members with a disability had a median income of \$39,155, below the overall family median income of \$50,046 for families without members with a disability. The data show that family income changes across disability types. For example, families with members with an intellectual disability had a median income of \$36,197, while families with members with a sensory disability or a physical disability had a median income of \$36,950.

Families reporting earnings from wages or salaries in 1999 were 73.1 percent of the total for families with members with a disability compared to 84.9 percent for families without members with a disability. Families with disabilities were more likely to receive

income from public programs (42.8 percent received income from Social Security compared to 22.5 percent of all families without members with a disability).⁴²

Diverse Ethnic Backgrounds

Ethnicity is a strong variable in the poverty and disability mix. Available data indicate that an average of 22 percent of African-American, American Indian, and Alaska Native families who have members with disabilities live in poverty. The rates are compared to 8.3 percent of non-Hispanic white families and 12.4 percent of Asian-American, Native Hawaiian, and other Pacific Island families.⁴³ Nationally, 28.9 percent of the 72.2 million families reported members with a disability. The disability prevalence rate among families reporting one or more members with a disability was 38.5 percent for American Indian and Alaska Native householders; 35.7 percent (2.9 million) for African-American householders; 33.2 percent (2.5 million) for Hispanic householders; 27.1 percent for non-Hispanic white householders; and 26.5 percent for Asian-American householders.

Over the past 30 years, 500,000 to 1 million people have come to the United States yearly from other countries. Today, one in 10 Americans is born outside the United States, compared to one in 20 just 30 years ago.⁴⁴ Since the September 11, 2001, attacks, the number of people granted legal permanent residence in the United States has dropped. For example, the FY 2003 number was fewer than 706,000 (34 percent), down from 1.06 million in 2002.⁴⁵

Social Spending History in the United States

For developing countries, the modern age of social spending dawned in the 18th century, when less than 1 percent of any one country's gross national product (GNP) was spent on welfare, unemployment, pensions, health, and housing subsidies.⁴⁶ Today in the United States, federal spending on just three social programs, Medicaid, Medicare, and Social Security, accounts for 42 percent of all federal outlays—compared to 2 percent of federal spending on social programs in 1950 prior to the creation of these programs.⁴⁷ Since the 1950s, the United States' federal outlays have averaged 20 percent of the GDP and composition of this spending has changed as well, with

mandatory programs now representing over 50 percent of federal spending compared to one-third in the early 1960s.⁴⁸

During the time of Adam Smith and Thomas Jefferson, there were practically no social programs (education included) for elders, individuals with disabilities, or children except for “poor relief.” Although the concept of the government’s taxing its citizens for education was discussed, it did not begin until the 19th century in the United States.⁴⁹ A rare exception was the military half-pensions that began during the Revolutionary War for veterans permanently disabled by combat-related injuries. It is reported that between 1880 and 1920, expenditures to provide pensions for aging veterans and veterans with disabilities of the Grand Army of the Republic grew to a quarter of federal expenditures.⁵⁰ Spending by towns for individuals who were blind began in the early 1800s, as did funding for institutions to house individuals with disabilities.

The United States in FY 2004 reported its largest deficit since the end of World War II at \$412 billion, representing 3.6 percent of the GDP.⁵¹ The Congressional Budget Office (CBO) projected the increases that would be needed in the public debt, which results in a \$2,234 trillion increase⁵² since 1997 (at the writing of this report the public debt stood at more than \$9 trillion dollars).⁵³ Mandatory outlays representing over 50 percent of federal spending are projected to grow by \$339 billion, from \$1.385 trillion for FY 2006 to \$1.724 trillion for FY 2010.⁵⁴ Discretionary outlays were projected to grow by \$65 billion, from \$915 billion for 2006 to \$980 billion for 2010.⁵⁵

The CBO reported that Medicare and Medicaid—the two major health care entitlements—consume a growing share of the nation’s economic output, having risen from 1.0 percent of GDP in 1970 to 4.2 percent in 2005.⁵⁶ The CBO provides projections and options for slowing spending for both Medicare and Medicaid that involve difficult choices and decisions about reductions, whether in the number of beneficiaries served, the amount of government support provided, or the types of services provided.⁵⁷

Recent findings from a report by NCD on long-term services and supports financing showed that there is no long-term services and supports policy for working Americans

with disabilities in the United States except for Medicaid, and that new funding mechanisms and new policy must be designed to meet the growing needs of individuals under age 65 who are working and have disabilities.⁵⁸ In addition, this report found that there are very few data on individuals age 65 and under with lifelong disabilities needing personal assistance services, transportation, housing, and services other than the functional limitation measurements of activities of daily living and instrumental activities of daily living; most research relates to the needs and costs of services for elders.

Similar to the growth in federal spending over the past 200 years, revenues have grown and have fluctuated between 16.1 percent and 20.9 percent of the GDP since 1951.⁵⁹ Like the change in spending priorities, the composition of revenues has changed, with the major portion coming from social insurance payroll taxes such as Social Security, Medicare, unemployment insurance, and retirement programs for federal civilian employees, and corporate income taxes and excise taxes decreasing.⁶⁰

The growth of social spending over the past 200 years is attributed to aging of the population, the rise in average income, and a shift of power and political voice to marginal populations (poor) as well as a change in voting rights.⁶¹ The United States experienced all four conditions in the 20th century as the population and income more than doubled, life expectancy increased by 30 years, and the civil rights legislation of the 1960s opened the door to voting and disability rights for all Americans.

Social Spending and Program Drift

An international study that examined the history of social spending of industrialized countries over the past three centuries found that with few exceptions, the distribution and redistribution of wealth from “the rich to the poor is least present when and where it seems most needed.”⁶² For example, during the period of 1985–1990, Lindert (2005) found that countries that were members of the Organization for Economic Cooperation and Development spent 16.3 percent of their GDP for social security or social insurance programs, compared to 2.7 percent in developing countries where the need was far higher.⁶³ Lindert describes this phenomenon as a “program drift” from “help-the-poor”

programs to big, broad social safety nets that give back many benefits to income classes that paid the tax originally.

This “program drift” is evident when one looks at spending and tax entitlements in the United States today. The Government Accountability Office (GAO), for example, identified a number of federal programs wholly devoted to serving mostly low-income individuals with disabilities as “high risk” and calculated the cost conservatively, when combined with costs of Medicare and Medicaid, to be over \$240 billion.⁶⁴ The GAO surveyed 20 different federal agencies that administer more than 200 disability programs (many of which are defined as financial incentives in this research) and found that 59 percent of the programs provided indirect support to people with disabilities through state grants, while the rest provided direct support to 34 million beneficiaries or clients.

Another study conducted by the Corporation for Enterprise Development, a private nonprofit, examined four tax entitlements that benefit homeowners, savers, investors, and small-business entrepreneurs. The study estimated that 98 percent of these four federal asset-building initiatives totaled \$345 billion and benefited individuals and households with incomes over \$50,000.⁶⁵ One-third of the assets went to 1 percent of Americans who earned over \$1 million, and less than 5 percent went to the bottom 60 percent of taxpayers.⁶⁶ The top 20 percent with incomes over \$81,000 received the largest share of tax benefits; the poorest 20 percent of taxpayers received an average benefit of \$4.24, while 1 percent with incomes \$1 million and over netted a benefit of \$38,107.⁶⁷ The research found that the “government gives up \$642 in revenue for every dollar spent on asset-building outlays.”⁶⁸

The study did not include asset policies that benefited corporations and included only a limited number of policies that benefited individuals. If corporate income tax revenues in 2004 were \$189.4 billion (1.6 percent of GDP), and when combined with state corporate tax revenues totaled \$225.8 billion (2.1 percent of GDP), one must wonder what the benefit amount to corporations would have been if asset policies that benefited corporations had been included.⁶⁹ It is clear that the two entitlements—spending

programs viewed mainly as safety net programs and tax spending—provide benefits to two very different groups of stakeholders and represent the phenomenon of program drift. Although some individuals with disabilities do own homes (less than 44 percent and less than 10 percent for people with intellectual disabilities), research shows that many do not take advantage of the home mortgage deduction.

Lindert's theory of program drift may explain why more than half of federal spending or tax entitlements are directed to nonpoor Americans.⁷⁰ The issue that will face 21st century policy analysts will be the struggle to balance market values with social values—a dilemma well known to the disability advocacy world. Charlton writes, “It is not easy to think about social phenomena in terms of dualities or paradoxes and contradictions but reality is complex and contradictory, no matter how much we yearn for something simpler.”⁷¹ Charlton describes the fundamental paradox facing the disability movement as the struggle “to incorporate differences into a strong, unified economy while simultaneously differentiating itself in the process.” Martha Minow, a Harvard law professor, suggests that the cultural and political focus on identifying disability has replicated rather than resolved the conflicting conceptions of individual freedom and social meaning.⁷² It is possible that the focus on the critical issues of integration and equal access dominated disability policy over the second half of the 20th century and that until now little attention has been paid to the integration and equity issues of financial incentives derived from federal spending and tax programs.

The Financial Incentives Project

The six subject areas identified for review in this study are education, employment, transportation, health care and long-term services and supports, income maintenance and asset development, and housing. Chapter 2 addresses these six subject areas and identifies and describes key financial incentives that exist in each of them. This chapter has established the background to begin formulation of a topology for looking at all expenditures, including those expenditures that are defined as incentives.

The proposed topology divides disability-related financial incentives into three broad categories: incentives involving direct payments (to people with disabilities), indirect payments (to third parties for disability-related purposes), and community-based expenditures. The community-based category includes services or programs that have a direct, intentional, or otherwise significant effect on the lives of people with disabilities in some way exceeding or differing from the impact on all other members of the community. In each of the six key subject areas, this report identifies and describes incentives falling into each of these three categories.

1.2. Conclusion

This chapter has introduced and described many of the key financial incentives, such as direct, indirect, and community based, to promote the full participation in society of people with disabilities. These incentives are grouped in ways that reflect their operation in a complex modern society. Some novel concepts have been employed to clarify how the incentives operate.

In attempting to create a flexible framework for understanding the range and impact of the incentives that exist today, this chapter lays the groundwork for a new policy vocabulary. By creating new categories into which most or all incentives, and for that matter disincentives, can be placed, this chapter has sought to create conditions under which various approaches, policies, and measures can be effectively compared, and through which the relationships among diverse measures, systems, laws, and funding streams can be understood integrally.

Chapter 2 will draw together research findings concerning the effects of these incentives, with a view to identifying which are successful and which are not. Chapter 2 also identifies some of the design features and factors for the proposed conceptual framework described in chapter 4. Such factors may have predictive value in determining the outcome of a particular incentive.

Chapter 2: Research Factors That Influence the Use of Financial Incentives: A Review of What Is Working and What Needs to Change for People with Disabilities Accessing Financial Incentives

The economic realities in which economists such as Smith, Richards, and Keynes lived are distant worlds away from the one we inhabit at the beginning of the 21st century, as indicated in *The Next Global Stage: Challenges and Opportunities in Our Borderless World*. (Kenichi Ohmae, 2005, Wharton School Publishing Pearson Education, Inc.)

2.1. Context for Review

This chapter includes information pertaining to each of the six domains and presents the information in terms of an introduction, purpose and method, and findings based on available research. With consideration for the limited volume of relevant evidence-based research, the information addresses the impact, outcomes, utilization, and challenges of financial incentives for individuals with disabilities.

2.2. Review of the Literature

2A – Education

Introduction

Financial incentives and disincentives have an impact on special education funding and practice, whether local, state, tribal, or federal.⁷³ Although substantive, evidence-based research exploring special education funding and practice in the United States is limited, this review will explore relevant available literature looking at how special education is funded in U.S. schools, along with its effectiveness and impact, with an eye toward unpacking financial incentives and disincentives as they relate to students with disabilities. This review also will look at the effectiveness of special education practice, with particular attention to its impact on the representation of students coming from

diverse cultural, linguistic, and economic status; students with disabilities in the judicial system; and postschool outcomes for special education students. Finally, this review will provide recommendations for research, funding, and practice in the broad field of special education.

Purpose and Method

The purpose of this section is to examine the evidence-based practices that demonstrate the impact of education financial incentives on the daily lives of individuals with disabilities. The research examines the direct, indirect, and community-based impact of education financial incentives. It also looks at whether education financial incentives work better for some individuals with disabilities than for others; the gaps in access and availability of education financial incentives for individuals with disabilities compared to individuals without disabilities; and what policy changes are needed to expand use of and participation in education financial incentives for individuals with disabilities. The findings from this section will be used to inform the recommendations for any changes or reform that will include a framework for congressional, legislative, and executive-level involvement.

2A:1 – The Individuals with Disabilities Education Act (IDEA)

Although the Americans with Disabilities Act of 1990 and Section 504 of the Rehabilitation Act of 1973 have broad application in schools, it is really the federal special education law passed in the mid-1970s that has had the most impact on students with disabilities.⁷⁴ Before the early 1970s, students with disabilities in the United States either received very poor educational services or were prohibited from attending school altogether. Largely as the result of advocacy on the part of parents, Congress first codified federal law regarding special education in 1975, with passage of P.L. 94-142, known as the Education for All Handicapped Children Act. Over time, this law has been changed, modified, and reauthorized several times. In 1990, its name was changed to the Individuals with Disabilities Education Act (IDEA), with another major reauthorization in 1997.⁷⁵ The most recent version of the act was reauthorized in 2004,

and its name was changed to the Individuals with Disabilities Education Improvement Act, attempting to align it with the recent No Child Left Behind legislation.⁷⁶

Findings

A key principle on which IDEA is based is that students with disabilities deserve a “free and appropriate public education” (FAPE). This principle was inserted into legislation in order to ensure that students with disabilities were no longer excluded from public schools—prior to passage of P.L. 94-142, many students with disabilities were not receiving education in public schools. In fact, OSEP reports that by 1975, Congress had determined that millions of American children with disabilities were still not receiving an appropriate education,⁷⁷ finding that “More than half of the handicapped children in the United States do not receive appropriate educational services which would enable them to have full equality of opportunity” (Education for All Handicapped Children Act (EAHCA), §3(b)(3)). Public Law 94-142 was enacted to remedy this situation by requiring that all students with disabilities receive FAPE and by providing a funding mechanism to help defray the costs of special education programs (Martin, Martin, & Terman, 1996).⁷⁸

- Along with the FAPE principle is the requirement that students with disabilities be educated in the “least restrictive environment” by being included in regular classrooms and regular schools (OSEP, 2006).⁷⁹
- In 2001, approximately 5.2 percent of children ages 3–5 received special education and related services in the United States and 12.1 percent of students ages 6–21 attending school received special education services.
- The number of students receiving special education services in both the group ages 6–12 and the group ages 13–17 grew during the 1992–2001 period. Forty-three percent of students ages 6–12 and 56 percent of students ages 13–17 had two or more disabilities. Disabilities included specific learning disabilities, speech/language impairments, intellectual disabilities, emotional disturbance, hearing impairments, visual impairments, orthopedic impairments, other health impairments, autism,

traumatic brain injury, multiple disabilities, and deaf-blindness. Boys represented about two-thirds of students with disabilities.⁸⁰

2A:2 – Funding of IDEA

Educational funding has changed substantially since the early 20th century in the United States. Then, schools were funded principally by tuition and charity mechanisms. Later, local taxes provided public school funding. State funding also was added to the mix to assist school districts that were not able to provide a minimum, foundational level of funding. Later funding mechanisms sought to establish equitable educational funding across poor and wealthy school districts. Currently, with the No Child Left Behind (NCLB) Act, both federal and state school funding schemes are tied to learning outcomes based on standardized tests.⁸¹ NCD is investigating the impact of both IDEA and NCLB on the educational outcomes for students with disabilities.

Findings

- Receipt of funding by states from the Federal Government for special education services is conditional on provision of a FAPE in the state for Part B of IDEA. Part C of IDEA provides for services for infants and toddlers. According to the Congressional Research Service, federal funding of IDEA has grown substantially in recent years—over 250 percent between 1995 and 2005—to \$11.7 billion in FY 2005.⁸² Although there is overall growth in special education funding appropriated for FY 2006, K–12 funding actually has gone down slightly.⁸³
- According to data from the Special Education Expenditure Project⁸⁴ (SEEP), total special education funding for students with disabilities in the United States was \$77.3 billion for school year 1999–2000.
- In constant dollars, SEEP found that the total special education per-pupil cost (which includes both special and regular education dollars) rose by 110 percent between school years 1968–1969 and 1999–2000.

- The \$77.3 billion total special education funding reflects \$12,474 per student receiving special education services in the United States for school year 1999–2000. The special education per-pupil cost was slightly less than half the per-pupil cost of students who were not receiving special education services. Put another way, the cost of providing regular and special education services to students receiving special education was 1.90 times the cost of providing education services to students not receiving special education in school year 1999–2000. This reflects little change from the estimated 1.92 times the cost of providing education services to students not receiving special education in school year 1968–1969.⁸⁵
- During the school periods 1968–1969 through 1999–2000, total per-pupil cost for all students (both special and regular education) rose 140 percent.⁸⁶

2A:3 – Effectiveness and Impact: Evaluating Educational Funding for Special Purposes

Concerns about the effectiveness and impact of educational funding are not new. The same concerns have been expressed about the effectiveness and impact of educational funding for special purposes, some as early as almost half a century ago.⁸⁷ Yet there is little evidence-based research exploring these concerns. Some argue about what that research should explore. A broad exploration of the utility of educational funding in general found that it would be helpful to evaluate the effectiveness of individual interventions rather than to explore the effects of large educational programs in aggregate, because federally funded educational programs allow a great deal of grantee flexibility in how to use that funding.⁸⁸

Findings

- In spite of large increases in educational funding over the last decade, funding levels continue to fall short of what is necessary to address the need. When Congress initially enacted special education legislation in the 1970s, it decided that it wanted to fund up to 40 percent of the “excess” cost of special education—the cost of educating a student with disabilities over and above the cost of educating a student

without a disability, which was felt then to be approximately twice the cost of educating students without disabilities.⁸⁹

- While Congress has steadily increased its funding levels over time, it has never come close to reaching its goal at the 40 percent level. In FY 2005, special education funding of Part B of IDEA (both as proposed by the President and as actually appropriated by Congress) did not even reach half the excess cost, at only 18.6 percent. Given a federal appropriation of \$10.6 billion for IDEA Part B in FY 2005, this left a balance of the estimated excess cost for students with disabilities of \$46.2 billion.⁹⁰ This balance is borne typically by local school districts already overwhelmed by budget shortfalls.⁹¹

2A:4 – Special Education Funding Models

Funding for special education to local school districts in the United States is provided in two different ways. Traditionally, funding is provided through child count—the number of students with disabilities is counted in a particular district, and funding provided to the district proportional to that number. The other special education funding approach is a lump-sum method.⁹² Child-count funding methods, referred to by some as a bounty approach, appear to encourage school districts to label students as having disabilities.

Findings

- One study done at the Manhattan Institute for Policy Research found a direct correlation between child-count funding methodologies and the increase in the number of students with disabilities. According to research, lump-sum funding methods remove this incentive. While some have argued that the increase in the number of students with disabilities reflects either a real increase in the incidence of disability or the effect of high-stakes testing, the Manhattan Institute for Policy Research study found no such effects.⁹³
- A cross-national comparative study of special education funding practices described two different modes of funding: supply-oriented and demand-oriented funding.⁹⁴ The

study defined supply-oriented funding mechanisms as the traditional approach to funding special education, in which students with disabilities are moved from their neighborhood schools to special (“segregated”) schools, where specialized supports are congregated. Control of special education funds and resources is held at the district, sometimes interdistrict, level, with only limited control at the school building level. Researchers saw this funding approach as a disincentive to the inclusion of students with disabilities in regular education schools and classrooms.

- The authors then outlined another funding approach, demand-oriented or pupil-bound funding, in which funding goes directly to local schools and is completely under local school control. Decisionmaking happens much closer to student and family, and was described as offering more incentive to at least the physical integration (if not necessarily always the social inclusion) of students with disabilities.
- In the countries using a demand-oriented approach, researchers found that parents had control over whether students could be included in regular education schools and classrooms, and that they could choose between schools (if available). Objective criteria for developing budgets for individual students were not developed in countries using a demand-oriented approach. Using demand-oriented approaches does not mean that inclusion will then be a foregone conclusion, the authors point out.
- Voucher approaches have been variously proposed and implemented. With only a few exceptions, according to a NCD (2003) study, special education has been left out of model voucher programs. Where special education has been included, programs may not serve as an appropriate model for replication. Substantial research is needed before voucher approaches can be applied broadly in special education.⁹⁵

2A:5 – Disincentives and Incentives for Inclusion

A report by the NCD (1995) found that significant state funding barriers prevented students with Individual Education Programs (IEPs) from receiving educational services in anything but segregated settings.⁹⁶ In a preliminary study of the cost of inclusion,

researchers at the Center for Special Education Finance found similar problems at both state and local levels. Education agencies allocated the most funds when special education and related services were provided in segregated or separate education environments. Such practices created disincentives for educating students with disabilities in regular education schools and classrooms. Finance reform that encourages educational intervention for all students, funding following students, and direct training would support a move away from disincentives.⁹⁷ Funding reforms alone, it was felt, would not be enough to change where students with disabilities receive special education services.⁹⁸

Findings

- According to the 1995 NCD study on inclusionary education referenced above, inclusion was no more expensive, and was perhaps often less expensive, than providing education to students with disabilities in segregated settings.⁹⁹ Conclusions from data gathered for the Center for Special Education Finance, also were that cost savings may be realized as the result of implementing inclusive special education services. The studies point out that districts implementing inclusion reform did so as a move toward best educational practice rather than to save money.¹⁰⁰

2A:6 – Other Funding Streams

There are roughly 200 programs, across 20 separate federal agencies, providing supports and services to people with disabilities, with a funding level of over \$120 billion in 2003 for programs focused solely on people with disabilities. Of that funding, 8 percent was spent on education. The Department of Education alone administers 33 programs either wholly or partially targeted to people with disabilities. Among other issues related to these many programs, there are concerns regarding the interaction among them.¹⁰¹

Findings

- One study by the Government Accountability Office (1999) looked at the interaction between Medicaid (which funds medically related services for students with disabilities in schools) and IDEA. The report, which looked at 12 states, found problems related to coordination, including identification, documentation, and a lack of federal guidance.¹⁰²
- Another funding stream that impacts students with disabilities comes from the Higher Education Act. NCD (2003)¹⁰³ found little research about the impact of funding on the postsecondary education outcomes of students with disabilities. NCD encouraged the Federal Government to improve access to postsecondary education for students with disabilities.
- The GAO (2005) investigation found differences between the percentages of children determined eligible for services (which ranged from 1.3 to 7.1 percent, depending on the state). States had differences in assessment and eligibility criteria, as well as differences in sources of funding. States were encouraged to concentrate on improving efforts to make the transition from Part C to Part B services seamless.¹⁰⁴

2A:7 – Rights and Inclusion

Families and people with disabilities indicate that changes in the IDEA legislation and supporting regulations, over time, have moved laws farther away from protecting the rights of students with disabilities and their families and closer to protecting the interests of school systems. Others have expressed concern that the Department of Education has not done enough to ensure that students with disabilities, perhaps especially people with the most severe disabilities, receive educational services in the least restrictive environment.¹⁰⁵

Findings

- Based on Office of Special Education Programs (OSEP) information,¹⁰⁶ fewer than half of students ages 6–21 receiving special education services spent most of their time (80 percent or more) in regular education classrooms in 2000, and almost 20 percent spent more than 60 percent of their school time in segregated classes, outside of regular education classrooms. A full 4.2 percent of students with disabilities in the 6–21 age range received their education in completely segregated settings outside of regular education buildings (residential facilities and other separate facilities, or in homebound or hospital environments [terms used in the OSEP data]). Students with deaf-blindness, multiple disabilities, and emotional disabilities were the most likely to receive educational services in completely segregated settings. Even when receiving their education in regular education buildings, students with intellectual disabilities, autism, multiple disabilities, deaf-blindness, and emotional disabilities were likely to spend most of their time in segregated classes outside of regular education classrooms.
- The Congressional Research Service also expressed concern that some provisions of NCLB may be disincentives to inclusion of children with disabilities, and in conflict with the provisions of IDEA. NCLB testing and accountability measures may force IEP team decisions that exclude students with disabilities from regular education curricula. While regulations have been proposed to address this issue, they have not yet been implemented.¹⁰⁷

2A:8 – Overrepresentation in Special Education of Students from Diverse Racial and Ethnic Groups and Students from Families Living in Poverty

Overall, there are significant achievement gaps between whites and students of other racial and ethnic groups in U.S. schools. For example, research indicates that graduation rates are substantially lower for students from diverse racial and ethnic groups.¹⁰⁸

Findings

- African-American students are much more likely to be identified as having intellectual disabilities and emotional disabilities than are whites.¹⁰⁹ OSEP data¹¹⁰ indicate that African-American students are almost three times more likely to be labeled as having intellectual disabilities, and well over two times more likely to be labeled as having an emotional disability, than all other racial and ethnic groups combined.
- African-American students are much more likely to be educated outside of regular education classrooms than are students from other racial and ethnic backgrounds.¹¹¹ More than twice as many African-American students with disabilities as white students spend at least 60 percent of their time in segregated-by-disability classrooms. The Special Education Elementary (SEELS) Parent Survey¹¹² found that students with disabilities from impoverished backgrounds, and African-American students with disabilities, were much more likely to be retained in grade than nonimpoverished or white students.
- Based on a review of achievement literature, 14 factors influenced the achievement gap between students of different racial/ethnicity groups and income levels.¹¹³ Birth weight, lead poisoning, hunger and nutrition, reading to young children, television watching, parent availability, student mobility, parent participation, rigor of curriculum, teacher experience and attendance, teacher preparation, class size, technology-assisted instruction, and school safety were found to correlate highly with student achievement. All factors influenced the achievement gap between students of different racial/ethnic groups and income levels.¹¹⁴

2A:9 – What Happens after Students with Disabilities Leave School?

One way of determining the impact of special education on students with disabilities is to explore their postschool experiences. What happens to students with disabilities after they leave school? What are their lives like?

Findings

- One study used data from the National Longitudinal Transition Study (NLTS) of Special Education Students conducted in 1987–1991, and the 1988 National Educational Longitudinal Study.¹¹⁵ Using a statistical analysis, the 1987–1991 NLTS of Special Education Students found that 40 percent of former special education students in the 18–26 age range lived at home, were single, were unemployed, and were not attending postsecondary education. Many of the remaining former special education students were employed, had started families, and had attended postsecondary education.
- The President’s Committee for People with Intellectual Disabilities (2004)¹¹⁶ reported that as students with intellectual disabilities, especially people between 18 and 21 years of age, transition from educational opportunities to the world of work they may experience situations in which there are conflicts between special education and community support funding practices and incentives, limiting their employment and training options. Only 15 percent of people with intellectual disabilities attended any kind of postsecondary education in 2002.¹¹⁷
- A 2003 Government Accountability Office study¹¹⁸ found several reasons that the transition from school to postsecondary employment and living was complicated for students with disabilities and their families: they did not have enough information about other resources (for example, vocational rehabilitation); service providers had inadequate capacity to serve students with disabilities seeking services from those resources; and transportation was lacking.
- A qualitative study by the Youth Advisory Committee for NCD found that even when adults with disabilities do seek postsecondary education experiences, they are unable to obtain the necessary financial aid.¹¹⁹

2A:10 – A Universal Design for Learning

One mixed-methods project exploring policy and practice implications of state-level reform legislation for students with disabilities and at-risk students found that reforms

need to focus on positive outcomes for all students, not just students with disabilities or students who were at risk. The same project suggested the need to make appropriate professional development resources available for all educators and administrators, not just people who teach or administer special education and related services.¹²⁰ It is essential to develop education policy that systematizes shared responsibility for the needs of all students and ensures that pre-service and in-service teachers and administrators have the knowledge, resources, and experience to deliver differentiated instruction to all students.¹²¹ Funding and implementation of best educational practices must be available to ensure that entitlement.

2B – Employment

Introduction

While the findings in this section focus narrowly on the financial incentives targeted to improving and increasing the employment of people with disabilities, NCD had previously published a report examining issues, practices, and recommendations focused on the employment of people with disabilities. According to data in Kosculek's 2004 report, people with disabilities, compared to their peers without disabilities, remain significantly unemployed or underemployed despite such policies as the Rehabilitation Act, the Individuals with Disabilities Education Act, and the Ticket to Work and Work Incentives Improvement Act.¹²²

Purpose and Method

The purpose of this section is to examine the evidence-based practices that demonstrate the impact of employment financial incentives on the daily lives of individuals with disabilities. The research will include direct, indirect, and community-based impacts of employment financial incentives. This will include examination of whether employment financial incentives work better for some individuals with disabilities than for others; the gaps in access and availability of employment financial incentives for individuals with disabilities compared to individuals without disabilities; and what policy changes are needed to expand utilization of and participation in

employment financial incentives for individuals with disabilities. The findings from this section will be used to inform the recommendations for any changes or reform that will include a framework for congressional, legislative, and executive-level involvement.

2B:1 – Vocational Rehabilitation

Findings

By far the greatest federal expenditures in rehabilitation services occur through the federal/state vocational rehabilitation (VR) system.

- For all reported VR closures in FY 2003, only 35 percent of closures represented successful employment outcomes (defined as completion of an Individual Plan for Employment [IPE]), but those closures cost 65 percent of the total funding of purchased services. The numerical outcomes for VR closures in FY 2003 show a slight decrease from comparable data extracted from the FY 1996 Rehabilitation Services Administration 911 database by Berry et al. (2000). People exiting the VR system with a successful employment outcome were 36.8 percent of the total; within this total, 39.7 percent of transition-aged individuals (ages 16–24) achieved such outcomes.¹²³
- During the last 25 years, a significant change in vocational rehabilitation strategies involved two parallel transitions of many individuals with severe disabilities. For some people with severe disabilities, the transition was from segregated institutions to community-based sheltered workshops; for others, it was from sheltered workshops to competitive employment, many through the relatively new “supported employment” strategy. Blanck, Schatz, and Schatz (2003), in their study of these transitions in seven states, indicate again the difficulty in accurate outcome measurement because of the use of nonstandard definitions of employment outcomes. The researchers found that while sheltered employment was a gateway for some individuals with intellectual disabilities into eventual supported employment, accompanied by an increase in earnings, this group represented only a small proportion of the sampled populations.¹²⁴

- Cimera (2000) reviewed 21 studies published since 1980 that investigated the cost-benefit ratio of supported employment programs, and found that all reported at least some positive benefits (i.e., ratios above 1.0) for federal/state VR dollars spent.¹²⁵
- Lee, Yoo, and Peters (2003), adapting a similar U.S. economic methodology to supported employment programs in Korea that were modeled after American developments, emphasized the need for longitudinal studies. Differing cost-benefit ratios for supported employment programs were obtained when sufficient time was allowed for start-up costs to decrease to annual operating expenses while the earnings of program participants grew significantly year by year.¹²⁶
- A primary source of evaluative data with respect to the vocational rehabilitation system derives from the Longitudinal Study of the Vocational Rehabilitation Services Program (LSVRSP), as mandated by the 1992 Rehabilitation Act Amendments. The Research Triangle Institute conducted a study of the decade 1992–2002 for the Department of Education, Rehabilitation Services Administration (RSA). The study's database, final reports, and published research relating to the LSVRSP are available on the RSA Web site and through the RRTC at Cornell University (www.ilr.cornell.edu/ped/lsvrsp) and the Disability Institute at the University of Illinois (<http://compaq.ncsa.uiuc.edu:8080/vrsp/do/overview>). The availability of this database provides researchers and others the opportunity for many research studies.¹²⁷
- The Tashjian and Schmidt-Davis (2000) study reported three key findings. First, the average cost for a single study participant was \$4,921, almost 20 percent higher than the approximate \$4,000 cost for the nonsupported employment successful completer of an IPE. Second, individuals who obtained a supported employment position worked an average of 23 hours per week and earned an average of \$4.53 per hour, compared to other successful consumers with significant disabilities, who worked an average of 34 hours per week and earned an average hourly wage of \$7.20. Third, on average, individuals with intellectual disabilities in supported employment earned virtually the same wage (\$4.21) as did individuals with

intellectual disabilities who exited VR services into other forms of employment (\$4.19).¹²⁸

- We may conclude that, with availability of the RSA 911 database of state vocational rehabilitation performance outcomes and the data in the LSVRSP, many research questions about the relative costs and benefits of VR programs (e.g., sheltered employment, supported employment, and competitive employment) and comparability of costs and benefits between state programs can now be addressed.

2B:2 – Ticket to Work

The Ticket to Work and Work Incentives Improvement Act of 1999, while it resulted from the contributions of many disability researchers and advocates, can trace one clear origin to economist Monroe Berkowitz (1997),¹²⁹ who has long recommended that vocational rehabilitation services for Social Security disability recipients be privatized. The resulting legislation established a national system of employment networks as community-based alternatives to the vocational rehabilitation system, created a national system of benefits planning, assistance, and outreach programs, and extended the Medicare coverage of individuals returning to work to a new maximum of eight and a half years.

Findings

- The most recent data published by Maximus, Inc. (the Ticket to Work Program manager under contract from the Social Security Administration) illustrate the lagging effectiveness of this program, which was five years old when this NCD report was developed, with Ticket to Work roll-out operations beginning in February 2002.
- The lack of overall success of the Ticket to Work Program, as currently structured, was highlighted in a Government Accountability Office report to the Social Security Administration (2005). Within the Ticket to Work Program, the small number of community-based organizations operating as employment networks (ENs), the small number of Ticket to Work holders working beyond substantial gainful activity (SGA),

and the small number of actual payments to ENs were cited by both the Ticket to Work Advisory Panel (2004)¹³⁰ and the GAO report. The GAO report called for research planning to test more effectively the changes suggested in the Ticket to Work Program by the Ticket to Work Advisory Panel and others.¹³¹

2B:3 – Department of Labor: Disability Program Navigators

The Workforce Investment Act of 1998 (WIA) established, among other programs, statewide workforce network councils under each state governor, and a number of workforce investment boards, varying by state population size. In turn, each workforce investment board was to certify a varying number of One-Stop Centers, in which both mandated federal programs and voluntary private-sector partner organizations were to be co-located. Included in the WIA legislation was the reauthorization of the Rehabilitation Act of 1973 (as amended in the intervening years). This legislation thus made each state vocational rehabilitation agency a mandated One-Stop Center Program. People with disabilities became eligible in many instances to receive federal training and employment benefits outside of their state VR agency. The U.S. Department of Labor is responsible for overall WIA program management.

Findings

- Early program implementation revealed that people with disabilities continued to encounter a number of serious barriers to the participation WIA mandates.¹³² WIA Standardized Records Data figures indicate that individuals with disabilities (i.e., people who self-report their disability) continue to be underrepresented in the WIA programs. However, Holcomb and Barnow (2004)¹³³ indicate that such voluntary self-reporting may result in an undercounting of individuals with disabilities actually served through the various WIA programs.
- In response to such findings, the Department of Labor and the Social Security Administration jointly created the Disability Program Navigator (DPN) Program, a \$24 million initiative in 17 states where SSA previously implemented employment support initiatives. At the writing of this report, 450 Disability Program Navigators

were serving one or more workforce investment areas in 30 states and the District of Columbia.

- Disability Program Navigators are people with training and experience in the workforce and rehabilitation systems who are employed by the workforce investment boards to work with the One-Stop Centers to enhance interagency program coordination and to facilitate access to the various programs for WIA customers with disabilities. Morris (2005) made the following preliminary observations from an evaluation of the DPN Program nationally.¹³⁴
 - Enthusiasm for the DPN Program is strong from all levels of participants interviewed.
 - There is more interagency cooperation, with Navigators building infrastructure and serving as valuable resources.
 - Participants at all levels want to see the DPN initiative continue and become imbedded as a natural position within the One-Stop system.
 - Satisfaction ratings were high:
 - Overall satisfaction was 7.54 on a 1–9 scale.
 - DPN services exceeded “expectations” (7.01 on 1–9 scale).
 - DPN services rated well when compared with an ideal set of services (6.65 on 1–9 scale).
- In the case of the Colorado WIA system, of the 291,770 recorded job seekers, 11,379 (3.9 percent) were people with disabilities; of the 1,458 WIA customers served by the DPNs, 81.2 percent were people with disabilities. However, while 10.4 percent of the WIA customers with disabilities received DPN services, only 2.0 percent and 5.9 percent received WIA training services or WIA main program services, respectively. Almost all (91.1 percent) received some service; 67.9 percent conducted a job search, and 52.8 percent were referred to a job opening; these constitute the WIA “core services,” with the least additional funds invested in the individual customer.¹³⁵

2B:4 – Cash Benefits and Work Incentives for Employment

The two primary cash benefit programs for people with disabilities are Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). SSI is a “safety net” program for recipients whose earned income record is insufficient to have created a work history (taxable work for 10 quarters), whose current resources are less than \$2,000, and whose low income qualifies them. SSI payments derive from the general federal treasury. SSDI benefits are paid to beneficiaries with a work history, with the monthly amount based by formula upon their previous earnings. SSDI funds derive from a trust fund created by each worker’s Federal Insurance Contributions Act (FICA) taxes. Table 5 presents current data for these two programs.

Findings

- Given the interrelationship between the SSDI Program operated by the Social Security Administration and the Vocational Rehabilitation Program operated by the Rehabilitation Services Administration, the success of these programs in terms of employment outcomes is difficult to ascertain.
- However, Berry et al. (2000)¹³⁶ found that most often services were provided to transition-age young people with disabilities (SSI participants) exiting vocational rehabilitation programs. According to Hergenrather et al. (2003), “Only 27 percent of SSDI beneficiaries received one of the public vocational rehabilitation services. Of these, job placement was used by less than 2 percent of beneficiaries. Less than one-fourth of one percent (.25 percent) of SSDI beneficiaries returns to work through public vocational rehabilitation.”¹³⁷
- Berry et al. (2000) reported that job-finding services were provided to 57.7 percent of SSI participants versus 43.2 percent of nonparticipants, and for job placement services, the percentages were 51.8 percent and 33.3 percent, respectively. No other analyses of the VR-SSA disability relationship were discovered.
- In a 2004 Congressional Budget Office study, the percentages of disability and early retirement were slightly lower for women. Among these SSA disability beneficiaries,

24 percent of men and 34 percent of women lived with incomes below 100 percent of the federal poverty level. Thus, while the SSA disability system was designed primarily on the model of the Old Age and Survivors system to serve as a safety net for people who had to leave the workforce prior to age 62 due to disability, it still leaves between one-fourth of men and one-third of women in poverty.¹³⁸

- Among people qualifying for SSA disability benefits who are nevertheless able to perform work at less than SGA (a dollar-per-month threshold announced annually by SSA), the use of three “work incentives” shows a distinct pattern.¹³⁹ In the period 1990–2004, the mean number of the following work incentives per state was illustrative of a distinct pattern. PASS (Plan to Achieve Self-Support) grew from 44 in 1990 to a peak of more than 200 in 1994 and 1995, then declined precipitously to 92 in 1996 and further declined to a low of 32 in 2004. Impairment-Related Work Expenses (IRWE) followed a similar pattern, peaking at 195 in 1995 and ending at 137 in 2004. Blind Work Expenses (BWE) held steady in the high 80s from 1990 through 1995, then began a gradual decline to 57 in 2004. The declines in these three work incentives all followed a strongly worded General Accounting Office report (1996).¹⁴⁰ Many individuals with disabilities with PASS in 1995 found them abruptly rescinded by SSA field offices in 1996, causing financial disruption in those individuals’ vocational plans. Such data provide some indication of the trust relationship that needs to be established between SSA and individual disability beneficiaries when the latter choose to use a work incentive, and the problems caused by inadequate program management and precipitous changes.

2B:5 – Tax Incentives to Employment

In examining the tax incentives to encourage the employment of people with disabilities, review needs to focus on both sides of the labor market equation: the supply side and the demand side. Among the tax incentives designed to induce people with disabilities to offer themselves for employment (supply), the primary one is the Earned Income Tax Credit (EITC). For some undeterminable portion of all returns filed with an EITC claim, those taxpayers were able to use their EITC to both offset income tax before credits and

receive a cash refund. While the EITC is not targeted specifically to low-income taxpayers with earned income who have disabilities, they certainly are included. The EITC has enjoyed bipartisan congressional support since its establishment in 1975, and has proven among the most successful of all federal programs in raising low-income families out of poverty.¹⁴¹

Findings

- Ten states and the District of Columbia have enacted state EITC programs with refundable credits (i.e., even if zero taxes are owed), and five states have enacted nonrefundable programs modeled on the federal EITC.¹⁴² Low-income workers with disabilities can use the Retirement Savings Contributions Credit, which, as a pre-tax exclusion, further reduces taxable earned income, and thus increases the EITC.¹⁴³
- The success of the EITC in motivating low-income individuals to enter the workforce also stimulated a mid-1990s proposal for a Disabled Worker Tax Credit (DWTC).¹⁴⁴ The DWTC would provide approximately \$1,000 as a refundable credit *in addition to* the EITC, with similar ramp-up provisions (increase in the DWTC with increase in earned income up to a ceiling), and then a plateau of DWTC for a range of earned income, and then declining DWTC after a certain threshold of earned income is passed. Of particular interest, the DWTC was designed to significantly mitigate the “income cliff” faced by SSDI beneficiaries whose earned income exceeded SGA after the nine-month trial work period and three-month cessation period.
- In the linking of a policy proposal to both a successful IRS program and a problematic Social Security Program, the DTWC proposal provides a heuristic model for future such proposals. A chronic problem with the entire “patchwork” of cash benefits and work incentives for individuals with disabilities has been legislation targeted to one agency program, without consideration of how changes in that program would affect eligibility criteria and benefits, and so forth, in other programs. Finally, in support of policy analyses that led to the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA), decision-support software was developed by Virginia Commonwealth University under contract from the Social

Security Administration. The resulting application, WorkWORLD, enables policymakers, academic researchers, and benefits managers at all levels to model the *system effects* of changes in programs from the perspective of the impacted individual with disabilities.¹⁴⁵

- As employer subsidies, the Work Opportunity Tax Credit (WOTC) and Welfare to Work (WtW) are designed to lessen the costs of the perceived productivity gaps of the 11 targeted groups of low-income, lower-educated employees. Among the targeted groups, three groups (vocational rehabilitation clients, SSI recipients, and Ticket to Work employment network ticket holders) focus on people with disabilities. In FY 2003, 403,243 certifications were issued to employers by state agencies.¹⁴⁶ Of this number, 6 percent (down from 8 percent in FY 2002) were SSI recipients; 5 percent in both FY 2002 and FY 2003 were VR referrals to employers. (Ticket to Work holders were only added as a designated group in 2004.)
- As directed by the TWWIA legislation, the Government Accountability Office (2001, 2002) studied the usage of the WOTC/WtW, the Architectural/Transportation Tax Deduction (IRS Code, Section 190, Barrier Removal), and the Disabled Access Credit (IRS Code, Section 144). The GAO reports determined that these three tax incentives are underutilized, but noted that IRS does not provide disaggregated data on rates of usage by employers among the 11 targeted groups of the WOTC/WtW, and does not determine whether barrier removal and accommodations claimed were made by an employer for employees with disabilities or to provide greater accessibility for customers.¹⁴⁷
- Two other perspectives challenge the traditional disability and employment research paradigms to become more comprehensive. The first is the *asset development movement*, which focuses upon assets as a key variable in family movement out of poverty.¹⁴⁸ Among disability advocacy organizations, the World Institute on Disability provides its e-newsletter *EQUITY* and policy studies to professionals in both the asset-building and disability communities. Asset-building strategies conflict with the resource limits for many benefits programs, especially SSI, which has a \$2,000 limit for the duration of SSI payments. The growth in application of Individual

Development Account (IDA) legislation, at both the federal and state levels, provides some lessening of these resource limits, but has yet to overcome fully the SSI resource limitation¹⁴⁹ beyond the time limits of the IDA Program.

- The second perspective is the Family Economic Self-Sufficiency Standard, created by the Wider Opportunities for Women organization as part of a state-by-state movement to define what self-sufficiency means in each labor market, and to use that standard to measure policy decisions targeted to low-income families and individuals. Ultimately, the measure of the various disability employment assistance, cash benefits, work incentives, and tax incentives, both for employees and employers, is to assist people with disabilities to reach economic self-sufficiency. Much research must be done on existing programs' impacts, and the hypothesized systemwide impacts of proposed modifications, before this goal is within reach.

2C – Transportation

Introduction

Transportation is a key factor in the employment options, housing availability, health care access, and community living for individuals with disabilities. Assisting people in living independent lives, staying out of nursing homes for as long as possible, and maintaining steady employment will save more taxpayer money than maintaining institutional supports for individuals with disabilities. The private automobile is the transportation of choice for most Americans, and the design of the environment has contributed to this preference by making many trips difficult or impossible to complete by any other means. Even when public or mass transit is available, scheduling, routing, financing, capital investment, crowding, and other factors, including inaccessibility, may reduce its value for people who would choose to utilize it.

Purpose and Method

The purpose of this section is to examine the impact of transportation financial incentives on the daily lives of individuals with disabilities. The research will include direct, indirect, and community-based impacts of transportation financial incentives. The

effort will address whether transportation financial incentives work better for some individuals with disabilities than for others; the gaps in access and availability of transportation financial incentives for individuals with disabilities compared to individuals without disabilities; and what policy changes are needed to expand utilization of and participation in transportation financial incentives for individuals with disabilities. The findings from this section will be used to inform the recommendations for any changes or reform that will include a framework for congressional, legislative, and executive-level involvement.

2C:1 – Direct, Indirect, and Community-Based Impacts of Transportation Financial Incentives

There are many federally funded human service programs that assist people with nonemergency medical needs, job training, education, employment opportunities and placements, and other supportive services. These programs usually are managed by state and local human service agencies, such as departments of social services, departments of health and mental health, and area agencies on aging. However, many of these agencies' clients are "transportation disadvantaged"—that is, they are unable to provide their own transportation to these services as a result of an age-related condition, disability, or income constraints.¹⁵⁰

Findings

- The Federal Government manages 62 separate programs that can fund transportation services for individuals who are transportation disadvantaged. The Government Accountability Office reports that federally funded transportation programs are administered through eight federal departments. There are 23 programs in the Department of Health and Human Services, 15 in the Department of Labor, 8 in the Department of Education, 6 in the Department of Transportation, and the remainder in the departments of Veterans Affairs (VA), Housing and Urban Development, Agriculture, and Interior. The 62 programs are authorized by 25 separate pieces of legislation.¹⁵¹

- The extent of spending for services for transportation-disadvantaged clients is not fully known. Only 32 of the 62 federal programs identified by the Government Accountability Office track transportation spending in their accounting or information systems, or could provide an estimate of transportation spending. For these 32 programs, federal spending totals \$2.5 billion a year. Most of these programs require a state or local match for the federal funds, many of them at 50 percent. However, some of these programs do allow other federal funds to be used as the match. So, even considering only the partial data that is available on human services transportation, the combined federal, state, and local annual investment in these services is at least \$3 billion to \$4 billion.¹⁵²
- Coordination can lead to significant reductions in per-trip operating costs for transportation providers. The savings proposed through agency coordination can be used to expand services to people or areas not previously served. The potential benefits of coordinating human services transportation include the following:¹⁵³
 - Access to more funds and more sources of funds
 - Higher-quality and more cost-effective services
 - Enhanced mobility and better access to jobs, health care, shopping, and community facilities
 - More visible and customer-friendly transportation services that are less confusing to access

2C:2 – Architectural/Transportation Tax Deduction: IRS Code, Section 190, Barrier Removal

Businesses may take an annual deduction for expenses incurred to remove physical, structural, and transportation barriers for people with disabilities at the workplace. All businesses are eligible. Businesses may take a tax deduction of up to \$15,000 a year for expenses incurred to remove barriers for people with disabilities. Amounts in excess of the \$15,000 maximum annual deduction may be depreciated. The deduction is available every year. It can be used for a variety of costs to make a facility or public

transportation vehicle, owned or leased for use in the business, more accessible to and usable by people with disabilities. Examples include the cost of the following:¹⁵⁴

- Providing accessible parking spaces, ramps, and curb cuts
- Providing telephones, water fountains, and restrooms that are accessible to people using wheelchairs
- Making walkways at least 48 inches wide

The deduction may not be used for expenses incurred for new construction, or for a complete renovation of a facility or public transportation vehicle, or for the normal replacement of depreciable property. Small businesses may use the credit and deduction together, if the expenses incurred qualify under both sections 44 and 190. For example, if a business spent \$12,000 for access adaptations, it would qualify for a \$5,000 tax credit and a \$7,000 tax deduction. Although both the tax credit and deduction may be used annually, if a business spends more than what may be claimed in one year, it cannot carry over those expenses and claim a tax benefit in the next year. The amount spent is subtracted from the total income of a business to establish its taxable income. In order for expenses to be deductible, accessibility standards established under the Section 190 regulations must be met.¹⁵⁵

2C:3 – Federal Funds

Findings

- The Air Carrier Access Act of 1986 (ACAA)¹⁵⁶ imposes nondiscrimination and accommodation requirements on most commercial airlines operating in the United States. While ACAA is not a benefits law with federal funds appropriated, there are funds to support its enforcement by the Department of Transportation (DOT). Airlines are obliged to spend some money to comply with the law.¹⁵⁷
- Title II of ADA addresses rail and bus transportation. Amtrak, the nation's passenger rail service, receives direct federal support, both for capital and operational expenses. Although neither the precise sums in question nor the specificity of

appropriations language have yet been reviewed, it is clear that federal financial support to a third party (namely, Amtrak) does go toward making intercity rail travel more accessible.¹⁵⁸ Thus, Title II of ADA applies to this mode of transportation.

- Perhaps the greatest change in this nation's transportation resources over the past generation has been the development of paratransit as a supplement or replacement for fixed-route transit for people whose disabilities make the general system unusable, despite its accessible design. Paratransit, as operated by local or municipal transportation agencies, represents one of the closest approaches to a direct transportation subsidy to individuals. The other near approximation to direct incentives to individuals is the reduced fares required by federal law to be provided to passengers with disabilities on municipal transit systems. Neither paratransit nor reduced fare is means-tested. Both are status based, in that the recipient of the service or discount must be an individual with a disability (or, in the case of the fare subsidy, an individual over the age of 65). Eligibility for paratransit is made on an individualized, case-by-case basis. Beyond even individualized eligibility determinations, there is a further concept—disliked by many, but legal—called trip eligibility.¹⁵⁹ With trip eligibility people with disabilities, though eligible in principle, are granted or denied the service for particular or types of trips based on purpose of trip, destination, or other factors.¹⁶⁰

NCD identified that \$2.4 billion was spent on human service transportation, but it is estimated that more than 40 of the participating programs do not track transportation expenditures. Therefore, the full cost of transportation services is unknown.¹⁶¹

2C:4 – Financial Incentives for Transportation Work Better for Some Individuals with Disabilities than for Others

Findings

- The U.S. population is aging, and transportation is critical to helping individuals stay independent as they age. Access to transportation, whether by automobile or some other mode, is considered essential to independent living, allowing individuals to

gain access to the goods, services, and social contacts that support their day-to-day existence and quality of life. Both the number of older people and their percentage of the U.S. population are growing rapidly. Although many elders continue to drive for most of their lives, the growing size of the senior population will increase demand for alternative transportation services.

- For example, one study found that more than 600,000 people ages 70 and older stop driving each year and become dependent on others for transportation.¹⁶² The increase in the potential pool of elders needing mobility assistance will challenge federal, state, and local government agencies' ability to provide such assistance.
- In 2000, 35 million Americans, or 12.4 percent of the total U.S. population, were ages 65 and over, according to the U.S. Bureau of the Census. The Census Bureau projects that this group will double to 70 million people by 2030, representing 20 percent of the total population.
- As elders age, their ability to drive, walk, or use public transportation may become limited by reduced reaction time; deteriorating night vision; lessening ability to climb, reach, or stand; or other physical limitations.
- To help ensure that transportation-disadvantaged elders have access to health and medical care, employment, and other basic services, various federal programs provide funds for a range of senior transportation services to state, local, and nonprofit agencies that actually provide the services and, in some cases, also provide their own funds to support those services.¹⁶³
- If an individual is on Medicaid and is going to the doctor's office, he or she might be able to take only one type of transportation service in the community. If a person is an elder (compared to adults under the current retirement age) and is going to a meal service, there might be someone else that provides that ride, but the elder may not be able to ride on a vehicle if another person with a disability is going in the same direction at the same time, just because of the eligibility rules provided by that funding stream.¹⁶⁴

- Inadequate transportation is an even greater obstacle for people with severe disabilities. People with somewhat or very severe disabilities are more than three times as likely to think transportation is a problem (34 percent and 36 percent, respectively) as are people without disabilities (10 percent) and twice as likely as are people with slight disabilities (17 percent).¹⁶⁵
- Medical care transportation also affects decisions to reside in nursing homes. For example, from October 2003 until September 2004, 113 people reported that they would like to leave nursing homes in rural Kansas, but entered due to the need for transportation to and from medical care. Due to nursing home costs that must be paid by individuals, some people who are in a facility for more than 30 days will have their home utilities turned off for lack of payment, or will lose a home for lack of ability to pay for housing that they would otherwise be able to pay. Then they will step onto the Medicaid roster without a likely exit.¹⁶⁶
- The employment-related benefits of improving rural transportation options for people with disabilities have been demonstrated by a five-year project of the Association of Programs for Rural Independent Living (APRIL), funded by the Rehabilitation Services Administration, U.S. Department of Education. The purpose of the RSA project is to demonstrate effectiveness of a voucher model to provide employment-related transportation to people with disabilities who live in rural areas. APRIL reports that after the third year of the project, 482 consumers were served. Approximately 52 percent, or 250, were unemployed when they entered the project. A total of 117 people obtained employment after entering the project. Clearly, federal financial assistance for rural transportation is a good investment.¹⁶⁷

2C:5 – Gaps in Access and Availability of Financial Incentives for Transportation for Individuals with Disabilities Compared to Individuals without Disabilities

Findings

- The National Organization on Disability (NOD) reported that 30 percent of people with disabilities found transportation inadequate, compared to 10 percent of people

without disabilities.¹⁶⁸ Lack of transportation to and from work among people with and without disabilities working full-time or part-time was reported as a barrier as well.¹⁶⁹ Three out of 10 people with disabilities (30 percent) still have a problem with inadequate transportation, and 16 percent cite inadequate transportation as a major problem. By contrast, only 1 out of 10 people without disabilities (10 percent) have a problem with inadequate transportation, and only 4 percent say it is a major problem.¹⁷⁰

- The *Washington Post* found that MetroAccess, a service that transports riders who have disabilities in the Washington area, has had erratic service. “A blind lung transplant patient was stranded by MetroAccess four nights in a row this week; a Maryland man in a wheelchair waited at a Giant supermarket for four hours and called Metro 24 times before a MetroAccess ride finally appeared on Wednesday; and on Thursday, a physician said three patients had trouble getting to or leaving his D.C. dialysis clinic because of mistakes by MetroAccess.”¹⁷¹
- The presence of a disability is not the only determining factor in whether transportation is a problem; income also seems to play a large role. People with annual household incomes of \$15,000 or less, whether with or without disabilities, are much more likely to say transportation is a problem than people with annual household incomes of \$50,000 or more.¹⁷²
- The transportation gap between people with disabilities and people without disabilities has actually widened by 7 percentage points since 1998, when NOD and Harris began collecting this data. Nationally, almost 15 million people in this country have difficulties getting the transportation they need. Of these, about 6 million (40 percent) are people with disabilities. More than 3.5 million people in this country never leave their homes. Of these, 1.9 million (54 percent) are people with disabilities. About 560,000 people with disabilities indicate that they never leave home because of transportation difficulties.¹⁷³
- In a nation of over 290 million, a Bureau of Transportation Statistics (BTS) survey (see note 153) found that almost 15 million people have difficulties getting the transportation they need. Nationwide, more than 1 percent of people are homebound

because of unmet transportation needs. More than half of the 1.9 million people who are homebound are people with disabilities. Many have disabilities that severely limit their mobility, such as Alzheimer's disease, senility, or dementia. However, the BTS survey found that for over half a million people with disabilities, the reason they never leave home is specifically that they cannot get the transportation they need.¹⁷⁴

2C:6 – Policy Changes Are Needed to Expand Utilization of and Participation in Financial Incentives for Transportation for Individuals with Disabilities

Even where public or mass transit is available, scheduling, routing, financing, capital investment, crowding, and other factors, including inaccessibility, may all reduce its value for people who would choose to utilize it. Accessible transportation often is a powerful positive predictor of employment, and of several other important quality-of-life indicators, such as political participation, access to entertainment, socializing, and religious attendance. Likewise, inaccessible transportation limits the ability of people with disabilities to participate in these activities.¹⁷⁵

Findings

- The GAO has made recommendations¹⁷⁶ about coordination, and the departments of Transportation, Health and Human Services, Labor, and Education have taken subsequent actions related to several options outlined therein:
 - The departments of Labor and Education join the departments of Transportation and Health and Human Services as members of the Coordinating Council on Access and Mobility (Coordinating Council).
 - The members of the Coordinating Council develop and distribute additional guidance to states and other grantees that encourages the coordination of transportation services.
 - The member departments ensure that the Coordinating Council's strategic plan and each member department's strategic and annual performance plans have long-term goals and performance measures related to coordinating the

departments' programs and improving transportation for transportation-disadvantaged populations.

- The member departments link their Web sites to the Web site of the Coordinating Council and advertise the site in departmental correspondence and other outreach opportunities. In addition to these recommendations was the identification of several more general options for improving coordination—including developing improved leadership and establishing interagency forums at the federal, state, and local levels; harmonizing differing federal program standards and requirements; and providing financial incentives to encourage state or local agencies to coordinate.
- The departments of Transportation, Health and Human Services, Labor, and Education also have taken additional actions related to the other options outlined in the GAO report for improving coordination. In December 2003, the four departments launched a five-part coordination initiative, “United We Ride,” that is designed to help states and communities overcome obstacles to coordination. This initiative is designed to provide financial incentives for coordination and establish an interagency forum for communication.¹⁷⁷

- Programs that can fund incidental transportation services include health and medical programs or job-training programs.
 - For example, Medicaid, which is administered by the Centers for Medicare and Medicaid Services within the Department of Health and Human Services (HHS), spent an estimated \$976.2 million on transportation in FY 2001.¹⁷⁸
 - In addition, the Community Transportation Association of America identified several programs as routinely providing transportation for clients, including WIA programs, administered by the Department of Labor, and Vocational Rehabilitation Grants, administered by the Department of Education.
 - DOT also funds several programs that focus on the specific transportation needs of transportation-disadvantaged populations. For example, Job Access and Reverse Commute Grants are aimed at connecting low-income individuals to

employment and support services, and the Capital Assistance Program for Elderly Persons and People with Disabilities provides financial assistance to nonprofit organizations for meeting the transportation needs of elders and people with disabilities.¹⁷⁹

- The Committee on Transportation and Infrastructure Subcommittee on Education and the Workforce, Joint Hearing on Coordinating Human Services Transportation, attempted to address the following questions:¹⁸⁰
 - **What are the obstacles to successful coordination?**¹⁸¹
 - **Obstacles related to shared resources.** “Turf control” is a fact of life at all levels of politics. Some agencies fear loss of control over the quality and convenience of transportation services to their clients, and some clients fear changes to their services, such as mixing different populations (e.g., people with developmental disabilities and children). Additionally, there are concerns about the initial time, effort, and costs required to establish coordinated services.
 - **Obstacles related to programmatic differences.** Each federal program has specific eligibility requirements and rules that may limit potential partners. Program reporting requirements and funding cycles differ, as do some vehicle safety and driver qualification standards. Most basically, human service program managers are focused on individuals, while transportation officials are focused on systems.
 - **Obstacles related to leadership and commitment.** Federal agencies provide limited leadership and guidance on coordination. For example, the DOT/HHS Coordinating Council on Access and Mobility is not funded, and the Council’s Web site is not even linked to the HHS Web site. Many human service program managers are not aware of the Coordinating Council or its efforts. The Centers for Medicare and Medicaid Services has not provided sufficient guidance on how to coordinate Medicaid transportation with existing public transit or other transportation resources. The Federal Transit

Administration has disseminated coordination guidelines to transit agencies, but not to human service officials or programs.

- **What are some potential options to improve coordination?**¹⁸²
 - Federal or state program managers could provide financial incentives or additional mandates to encourage coordination. An example of financial incentives is in Florida, where direct funding is provided for coordination planning and operations, and “bonus points” are given in funding applications for state grants if services are coordinated. An example of a coordination mandate is the DOT Job Access and Reverse Commute Grant program, which requires that projects be part of a coordinated public transit-human services transportation planning process in order to be eligible for funding.
 - Federal agencies could harmonize program eligibility, reporting, safety standards, and funding cycles. Legislation and regulations could include common language, such as “and others, as space is available,” to explicitly encourage and allow coordination of transportation resources.
 - Federal and state agencies could provide additional technical guidance and information sharing. For example, the membership of the DOT/HHS Coordinating Council could be expanded to include other agencies involved in providing transportation, and the Council’s Web site linked to HHS, DOL, and Department of Education Web sites. Federal agencies could provide guidance to states and other grantees to clearly define allowable uses of funds and develop cost-sharing arrangements for transportation of common clientele.
- The reauthorization of the Transportation Equity Act presents a unique opportunity to improve access to transportation for the 56 million individuals with disabilities and their families. The Transportation Equity Act (TEA) contains several provisions that improve mobility for people with disabilities:¹⁸³
 - TEA-21 authorizes Project Action, which for 12 years has provided valuable technical assistance to transportation providers and people with disabilities and

contributed to making transportation one of the most accessible sectors of today's society.

- As a result of TEA-21, states can use federal surface transportation funds for the modification of public sidewalks to comply with ADA. Without accessible sidewalks, many people with disabilities are stranded, unable to take advantage of the investments made in the accessibility of the transportation system.
- The most recent reauthorization of TEA-21 added a requirement that transportation plans and projects provide due consideration for safety and contiguous routes for pedestrians, including the installation, where appropriate, and maintenance of audible traffic signals and audible signs at street crossings. As a result, states, cities, and counties are beginning to take advantage of assistance from the U.S. Federal Highway Administration and the U.S. Access Board to make their pedestrian environments accessible for people who are blind, visually impaired, or have deaf-blindness.
- Grants to assist over-the-road bus operators in complying with ADA have contributed to more accessible intercity bus transportation for people with disabilities.
- Transit enhancement funds include a set-aside of funds for certain transit improvements, including enhanced access for people with disabilities to mass transportation.

2D – Health Care and Long-Term Services and Supports

Introduction

Health care and long-term services and supports (LTSS) are critical concerns for the disability community. No single federal program or federal agency is charged with the responsibility for management, funding, and oversight of LTSS at home and in the community. More than 20 federal agencies and almost 200 programs provide a wide range of assistance and services to people with disabilities.¹⁸⁴ There is no single entry point at a community level for individuals with disabilities to learn about and access

service and support options. Thus, it is difficult for people to take advantage of existing financial incentives related to health care and LTSS.

LTSS is an issue for elders and for younger individuals with disabilities; any LTSS financing and system reform efforts must consider both populations. Although people who have disabilities have indicated a preference for receiving LTSS in home- and community-based settings, a federal institutional bias exists. Presently, about 1.6 million people live in nursing homes, group homes, and other institutional facilities.¹⁸⁵ At the same time, about 2 million to 2.4 million people are on waiting lists or in need of some type of LTSS.¹⁸⁶

Disability advocates are working with the health care industry to create a continuum of care, including such services as assisted living, adult day services, and home care. Issues include financing, supporting family caregivers, addressing workforce shortages, improving the quality of LTSS services, and improving access to transportation and housing. The development of a sustainable and affordable LTSS public policy funded through innovative private sector assistance and public support will provide security for individuals with disabilities.¹⁸⁷

Purpose and Method

The purpose of this section is to examine the evidence-based practices that demonstrate the impact of financial incentives on the availability of health care and LTSS for individuals with disabilities. The research will include direct, indirect, and community-based impacts of health care and LTSS financial incentives and disincentives. The work will focus on whether financial incentives work better for some individuals with disabilities than for others; the gaps in access and availability of financial incentives for individuals with disabilities compared to individuals without disabilities; and what policy changes are needed to expand utilization of and participation in health care and LTSS financial incentives for individuals with disabilities. The findings from this section will be used to inform the recommendations for any

changes or reform that will include a framework for congressional, legislative, and executive-level involvement.

2D:1 – Private Health Insurance and Unpaid Caregivers

Many individuals with disabilities must rely on sources other than federal or state assistance to meet their health care and LTSS needs. The Federal Government should strengthen partnerships with these entities.

Findings

- Forty-two percent of the cost of treating uninsured patients is shifted to private insurance.¹⁸⁸ As Medicaid becomes more stringent in its requirements for coverage, the burden will be placed on private insurers, even if uncovered patients do not seek private insurance.
- Managed care plans frequently limit beneficiaries to a closed network of providers. Since often there are only a few qualified providers with the specialized skills and experience in treating people with specific types of disabilities in a community, closed networks create a risk that people with disabilities will not have access to all the types of providers they need.¹⁸⁹
- Private insurance for long-term care is usually capped at a specific dollar amount, provides coverage for only about three years, and is geared toward services and supports that cater to diseases of aging and not the needs of everyday working Americans with disabilities.¹⁹⁰ In addition, only about 10 percent of Americans have private long-term care insurance.¹⁹¹ A recent actuarial study found that Americans at age 45 are more likely to become people with disabilities than to die, yet the industry continues to insure against loss of life rather than against the risk of disability.¹⁹²
- The estimated benefit of informal caregiving exceeds \$200 billion annually. Services should be designed to support, not supplant, the role of the family and actions of informal caregivers.

- One suggestion is to conduct a feasibility study of possible new insurance products and options regarding relationship to the Medicaid Program to evaluate possible strategies to partner an LTSS insurance product with supplementary Medicaid coverage for people with disabilities under age 65.¹⁹³ A feasibility study would need to consider price, benefit coverage, caps in coverage, and eligibility for Medicaid LTSS, and project market demand and needed incentives to share risk among stakeholders: the government, the consumer, and the insurance industry.¹⁹⁴
- Nearly three-quarters of individuals ages 18–64 receiving long-term care assistance rely exclusively on unpaid caregivers—usually family. Only 6 percent of people ages 18–64 years rely exclusively on paid assistance.¹⁹⁵
- Most states have regulations referred to as the “Nurse Practice Act.” The effect of the Nurse Practice Act may bar friends and family members from receiving funds for assistance defined as nursing, such as administration of medication, urinary catheterization, and gastrostomy tube feedings. States will need to amend their regulations so as not to impede the assistance of personal care attendants who are not nurses.¹⁹⁶

2D:2 – Medicare and Medicaid

There is not enough money to pay for any type of public program, expansion of existing programs, or long-term care for everyone.¹⁹⁷ This was substantiated when President Clinton signed the Long-Term Care Security Act in September 2002, establishing the Federal Long-Term Care Insurance Program for federal employees.¹⁹⁸ The program was the result of a three-year study that showed a need for this type of benefit, and it became a model for employers across the country.¹⁹⁹ Twenty-four states now offer a tax credit for residents who own a long-term care policy.²⁰⁰

Findings

- Medicaid has significant gaps in coverage that can limit the independence of individuals with disabilities.²⁰¹ The gaps in Medicaid coverage include limited

coverage for personal assistance services, institutional services, dental care and dentures, hearing aids, eye care, foot care, many screening tests, bathroom grab bars, and other assistive equipment.²⁰²

- Increasingly, states have chosen to eliminate or restrict coverage of a number of optional services for their adult Medicaid beneficiaries in order to contain program costs.²⁰³ States have broad discretion in determining the amount, duration, and scope of their covered Medicaid services.²⁰⁴ The distinction as to whether a benefit is mandatory or optional is somewhat blurred, regardless of how a benefit may be classified in federal law, since services regarded as medically needed are in each classification.²⁰⁵
- The growth in Medicaid spending is unsustainable. Eligibility and service pathways to the state Medicaid Program have expanded to meet the growing needs of 53 million low-income, middle-income, and uninsured acute care and LTSS beneficiaries, and reflect growing challenges of economic downturns, increased health premiums, increased longevity, a low savings rate, and slower wage growth.²⁰⁶ States cannot respond to current and future LTSS needs as long as health care costs continue to rise by double-digit rates.²⁰⁷
- The cost of long-term care accounts for a large portion of Medicaid spending. Of the more than 3.5 million Americans suffering from chronic conditions, severe mental illness, or developmental disabilities that necessitate long-term care, 37 percent of people receiving Medicaid long-term care benefits are under age 65 and account for 43 percent of Medicaid long-term care funding.²⁰⁸
- Medicare's coverage of long-term care is limited to postacute care through its skilled nursing facility benefit and home health care benefit.²⁰⁹ Accessing the postacute care services and supports through Medicare coverage of skilled nursing facility and home health care benefits is crucial to enabling millions to avoid far more costly hospitalization and long-term institutionalizations.²¹⁰
- In 2000, Medicaid paid for 45 percent of the total amount spent on long-term care in the United States.²¹¹ In FY 2004, total federal and state Medicaid expenditures on all

long-term care reached \$100.5 billion and accounted for 35.7 percent of all Medicaid spending.²¹²

- “Dual eligible” make up 24 percent of the cost of both Medicaid and Medicare.²¹³ Dual eligible are individuals who meet the requirements for both Medicaid and Medicare because of age and disability. The Robert Wood Johnson Foundation co-funded the long-term care study, which found that dual eligibles are most likely to be female, widowed, living alone, and with lower incomes than other elderly Medicare enrollees.²¹⁴ The study also found that among this population there are widespread shortfalls in access to long-term care. Among people surveyed, 56 percent reported serious consequences resulting from a lack of needed assistance, including falling out of bed, not being able to bathe, and soiling themselves.²¹⁵ This is an indication of how much vulnerable populations rely on Medicare and Medicaid, as well as the insufficiency of these programs in meeting the needs of the dual eligible.
- LTSS is not portable across states. The fiscal health of each state and its ability to provide the necessary match to draw upon federal Medicaid resources determine the scope and array of the current LTSS system for low-income Americans with disabilities. Therefore, the personal assistance needs of an individual in one state may be similar to those of an individual in another state, but the availability of services and funding may vary dramatically.²¹⁶

2D:3 – Waiver Authority

States currently operate more than 250 distinct waiver programs.²¹⁷ Waivers enable states to design programs that meet the unique needs of individuals with disabilities. Waiver programs are the fastest growing segment of Medicaid, with expenditures and number of people covered increasing annually by more than 10 percent.²¹⁸ These waiver programs constitute the principal way that states can offer services and supports that are consumer centered and promote independence and community participation among people with disabilities.

Findings

- Three federal initiatives that have demonstrated success are Real Choice System change grants, Independence Plus initiative, and Home and Community-Based Services (HCBS) waivers.²¹⁹ The Real Choice System change grants have been awarded to 238 recipients to foster systematic changes to enhance independence.²²⁰ States are using these grants for personal assistance services, direct service worker shortages, transitions from institutions to the community, respite service for caregivers and family members, and better transportation options.²²¹
- Similarly, SSA has waiver authority it can grant to states on a case-by-case basis to modify existing policies and procedures and encourage testing alternative policies and procedures that promote independence and self-sufficiency for individuals with disabilities and their families.
- On May 9, 2002, Tommy Thompson, secretary of the Department of Health and Human Services, unveiled the Independence Plus initiative in response to Executive Order 13217, in which HHS promised to provide states with simplified model waiver and demonstration application templates that would promote person-centered planning and self-directed service options.²²²
 - Independence Plus is based on the experiences and lessons learned from states that pioneered consumer self-direction. Two national pilot projects demonstrated the success of these approaches in the 1990s: the Self-Determination project in 19 states that focused primarily on the Home and Community-Based Services Section 1915(c) waivers, and the Cash and Counseling project in three states that focused on the Section 1115 demonstrations. These programs allowed service recipients or their families the option to direct the design and delivery of services and supports they received, with the goals of avoiding unnecessary institutionalization, experiencing higher levels of satisfaction, and maximizing the efficient use of community services and supports.²²³

- The Centers for Medicare and Medicaid Services (CMS) is consolidating the existing Independence Plus template into a new Web-based Section 1915(c) application with instructions. The consolidation enables the expansion of a variety of self-directed options in existing waivers; consistent participant protections across all waiver programs; minimal administrative burden to states; an easier waiver amendment process; and improved communication of expectations for quality.²²⁴
 - There are 11 approved Independence Plus waivers in 10 states, and several states are working with CMS to submit proposals.²²⁵
- In response to the increasing costs of nursing facility care and the institutional bias that was part of the initial authority in 1970, home health services became a mandatory benefit.²²⁶ In 1981, Congress authorized the HCBS waiver authority.²²⁷ The Section 1915(c) waiver, named after the section of the Social Security Act that authorized it, allows states to provide services not usually covered by Medicaid to keep a person from being institutionalized. Home and community-based services (other than room and board) for specific eligible populations are now part of waiver programs in all 50 states.
- In addition to the HCBS waiver authority, there is a Section 1115 waiver authority. Section 1115 of the Social Security Act provides CMS broad authority to support experimental, pilot, or demonstration projects to test new ideas related to the financing and delivery of medical and supportive services. A proposed experiment or demonstration under Section 1115 of the Social Security Act must be a program model that had not been tested previously and could not be conducted within the boundaries of a more limited waiver authority, such as the HCBS waiver. A Section 1115 waiver must be budget neutral over the life of a project, typically five years. In other words, the model cannot be expected to cost the Federal Government more than it would cost without the waiver. A number of states with current Section 1115 demonstration projects are testing managed care approaches covering acute and long-term care services. Other states are using Section 1115 authority to test self-

directed support plans, individual budgets, and the hiring of family members to provide services.²²⁸

- States may offer a variety of services to participants under an HCBS waiver program and are not limited in the number of services that can be provided. To be eligible under a specific HCBS waiver, an individual must meet targeting and service criteria. Targeting criteria may involve age, diagnosis, or condition. Most states have multiple waivers targeted to different groups, such as people with traumatic brain injury, people with AIDS, and people with intellectual and developmental disabilities.
- States must demonstrate that waiver services are being provided only to individuals who are eligible for institutional placement. Equivalent criteria for waiver services and for institutional placement stem from the SSA waiver program's primary purpose, which is to offer alternatives to institutional placement.²²⁹

2D:4 – Future Considerations

Findings

- The National Academy of Social Insurance Study Panel on Long-Term Care (LTC Study Panel) found that three tenets should guide the long-term care system of the future:
 - The needs of individuals should determine the kinds of services available.
 - Service delivery should preserve the autonomy of the people receiving services.
 - The costs of services should be shared equitably among individuals, families, and the society. Services should be similarly available and affordable regardless of the state in which a person lives.²³⁰
- The LTC Study Panel also found that nearly 10 million Americans need help with basic tasks of living, such as bathing, eating, dressing, or walking, or with other activities that maintain their independence, such as shopping, cooking, or cleaning. More than 80 percent of people who need care live in their communities, not in nursing homes, and nearly 40 percent of them are under age 65.

- The LTC Study Panel found that the current long-term care system falls far short of meeting reasonable expectations in several ways:²³¹
 - *Unmet needs.* Many people receive inadequate care. Nationally, 20 percent of people living in the community and needing services get less help than they need. As a result, they are more likely to fall, soil themselves, or be unable to bathe or eat.
 - *Burden on caregivers.* Unpaid caregivers play a critical role in the system but often pay an economic, physical, and emotional toll. Workers in the formal long-term care system labor under difficult conditions and low wages, frequently without fringe benefits.
 - *Financial jeopardy.* The cost of long-term care can impose financial hardship or even spell financial catastrophe for many families. Few people have any type of insurance against the expense of long-term care, which can reach \$26,000 a year at home and more than twice that amount in an institution.
 - *Limitations in Medicaid.* The federal-state Medicaid Program finances long-term care only for people who are or have become impoverished. Its benefits vary widely from state to state, and it requires some people who need help to move to institutions, when they would much rather live in their communities.
 - *Quality problems.* Serious quality problems persist in some nursing homes, partly as a result of inadequate staffing. Quality in noninstitutional settings is also a concern.
 - *Demographic challenges.* The long-term care system is unprepared to meet the demands that the baby boom generation will impose upon it. The coming demographic shift also will exacerbate staffing shortages.
- The LTC Study Panel identifies two promising approaches. Expanded federal financing could take one of two forms:
 - *Universal approach.* One option, modeled on Social Security, would provide everyone access to a basic, limited, long-term care benefit, supplemented by

private insurance for people who can afford it, and enhanced public protection for the low-income population.

- *Means-tested approach.* Another option would establish a national floor of income and asset protection that would reform or replace Medicaid's coverage of long-term care. People could purchase private long-term care insurance to protect a larger amount of assets.
- Further expansion of the federal role in long-term care financing faces significant obstacles. Congressional deliberations and debate among other policymakers focus on the scope of government, the roles of public support and private responsibility, and levels of spending and taxation. According to the LTC Study Panel, the public seems more receptive toward mixed public/private financing mechanisms than to fully public solutions.
- The LTC Study Panel also suggests that long-term care financing should include initiatives to promote the purchase of long-term care insurance, provide public coverage of catastrophic costs, mandate financial contributions to prefund long-term care, and provide more comprehensive public coverage.²³²
- LTSS needs among people from diverse racial and ethnic groups are greater than in the current U.S. majority population. The issues of poverty, lack of insurance, and continued segregation from affordable and consistent health care will increase the future needs and costs for LTSS for nonwhite populations in the United States, which are projected to make up 50 percent of the American population by 2050.²³³
- Better medical care has increased the life expectancies for the disabled, so there will be more people living with disabilities and requiring health coverage for a longer period.²³⁴ The result is that the composition of the Medicaid caseload is expected to shift toward an increasing proportion of elderly and disabled, the most expensive categories.
- Some believe that progress in the treatment of disabling conditions may eventually reduce the need for long-term care. Others suggest that the projected longer life span will mean individuals will experience more years of disability before death.

- There are precedents of successful programs for consumer-directed long-term care. For the past 30 years, the Veterans Administration has operated the Housebound and Aid and Attendance programs, which provide additional cash benefits to qualified veterans or their surviving spouses if they require ongoing personal care services, are housebound, or require nursing home services. This cash benefit provides the veteran with additional monthly income to purchase needed services and supports. There are no federal restrictions on how this additional cash benefit may be used. The veteran with a disability can determine how to spend the benefit; for example, he or she can hire friends or family members to provide personal care services. Two of the most common types of consumer-directed approaches are the individualized budget and direct cash:²³⁵
 - In an individualized budget, the state establishes a total dollar value for the services needed by the individual. The state contracts with an organization, such as a Medicaid provider, to track the individual's budget and, in some cases, to employ the direct care workers who are selected by the consumers. However, the consumer has discretion over what services he or she will receive and how much that direct care worker will be paid.
 - In the direct cash approach, the state also establishes a total dollar value for the services the consumer needs; however, the cash allotment goes directly to the consumer rather than the provider. The consumer recruits, hires, and manages the direct care worker. The direct care worker is employed by the consumer, does not have to be a certified Medicaid provider, and is not required to have a written contract with the state.²³⁶
- The *Olmstead* decision determined that states had a legal obligation to serve individuals with disabilities in a setting that reflected their preferences. States' responses to the decision have focused attention on increasing the capacity of Medicaid HCBS as an alternative to institutions such as nursing homes, and developing options that respond to consumer preferences. However, state budget shortfalls and declining revenues have affected the level of implementation.²³⁷

- There is concern about fraud and abuse in consumer-directed programs. However, many consumer-directed programs include policies and procedures to minimize fraud and abuse and maintain accountability for public funds, such as approving the consumer's plan for using the funding, tracking utilization of services, other forms of monitoring, and collecting receipts. Kevin Mahoney, national program director for the Cash and Counseling demonstration, after three and a half years, found "no major instances of fraud and abuse." The final report on the program in three original states (Arkansas, New Jersey, and Florida) noted that "Abuse of the allowance was almost nonexistent in the three Cash and Counseling programs."²³⁸
- Health care costs for mental illnesses in America are unknown, and the prevalence rate of mental illnesses is growing. The mental illness category is projected to rank number two after heart disease and replace cancer by 2010 as having a greater impact on death and disability.²³⁹ Medicaid is the principal public payer for mental health services and represents 36 percent of the \$48 billion in spending.²⁴⁰ It is unclear what the future LTSS needs and costs will be for people with mental illnesses.
- The public overestimates the help that is available from public disability insurance programs like SSDI and other state-mandated short-term programs. Workers compensation benefits cover only disabilities caused by injury or illness arising on the job, which accounts for only 4 percent of disabilities.
- There is a lack of data regarding the costs of LTSS for children and adults with disabilities. LTSS for people 65 years and younger includes many nonmedical services and supports such as personal assistance, assistive technology, financial management, housing, transportation, and nutrition.²⁴¹
- AmeriWell is a model suggested by NCD to cover the LTSS costs of all Americans.²⁴² AmeriWell is a prefunded, mandatory, long-term services and supports model that provides all Americans of any age with coverage from birth based on criteria of risk and functioning, not category of disability. AmeriWell delinks LTSS from Medicaid and Medicare, creating its own governing agency, regulations, oversight, and congressional committee. The contributions of individuals and

families, the private sector, and the Federal Government fund AmeriWell. A penny pool is established through private stock transactions to supplement LTSS costs for impoverished and vulnerable Americans previously served under Medicaid and Medicare.²⁴³

2E – Income Maintenance and Asset Development

Income Maintenance

Depending on one's definition, income maintenance and income replacement may represent the largest category of identifiable federal expenditures targeted to people with disabilities. Though varying in detail based on the prevailing assumptions at the time of enactment, all these programs take as their point of departure certain assumptions about the association of disability, in its own right or as mediated by inability to work, with poverty.²⁴⁴

Income maintenance or replacement programs can be divided into two basic groups: programs that provide cash and programs that provide in-kind assistance.

Purpose and Method

The purpose of this section is to examine the evidence-based practices that demonstrate the impact of income maintenance financial incentives on the daily lives of individuals with disabilities. The research will include direct, indirect, and community-based impacts of income maintenance financial incentives. Examination will include whether income maintenance financial incentives work better for some individuals with disabilities than for others; the gaps in access and availability of income maintenance financial incentives for individuals with disabilities compared to individuals without disabilities; and what policy changes are needed to expand utilization of and participation in income maintenance financial incentives for individuals with disabilities. The findings from this section will inform the recommendations for any changes or reform. In turn, the recommendations will include a framework for congressional, legislative, and executive-level involvement.

2E:1 – Social Security Disability Insurance

SSDI is one of the two key underpinnings of this nation's social insurance system. Available to workers who have paid into Social Security²⁴⁵ and to their dependents, SSDI replaces income for people rendered unable to work by reason of disability prior to normal retirement age. Benefit levels are predicated on meeting the SSA definition of disability, which includes both a diagnosis, a prognosis that the condition will last for at least a year or result in death, and a determination of the individual's inability to work.²⁴⁶ Although not means-tested, this linkage to the ability to gain income through work amounts as a practical matter to the equivalent of means testing in many cases. Benefit levels are linked to the amount of time the individual has worked, and to the individual's wages or self-employment income during that time.²⁴⁷

Findings

- Although SSDI is vital to millions of American families, it is hard to characterize it as an incentive. Despite the suspicions of many about SSDI, it is unlikely that people would deliberately seek to become people with disabilities (as opposed to claiming falsely to have a disability) in order to qualify for SSDI. In the end, the program is a community resource, designed to ensure stability and prevent destitution and rapid downward mobility.²⁴⁸
 - A key factor in understanding the role of SSDI as an incentive or disincentive in the lives of people with disabilities is its linkage to health insurance. Most people receiving SSDI also are eligible for Medicare.
 - While some SSDI recipients will be able to maintain private sector insurance, assuming they had it when they worked, through the coverage of a spouse at work, for a period of time through their former employment coverage under the Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA) (subject to full assumption of the premiums and a 2 percent administrative fee)²⁴⁹ or through other affiliations, Medicare is as crucial as cash benefits in the lives of many SSDI recipients.

- It is this close connection, resulting as it does in the potential loss of insurance coverage if work is obtained that does not include comparable insurance coverage, that perversely cements the relationship and the destructive dichotomy between disability and work in American public policy.²⁵⁰
- Of the 41 million Medicare beneficiaries, approximately 6 million under the age of 65 received Medicare on account of disability status in 2003.²⁵¹ According to recent research based on new SSDI beneficiaries in 1995 who qualified upon their own work record, 11.8 percent died within the waiting period for Medicare. The study estimated hypothetical Medicare costs for the first 24 months of SSDI entitlement to be \$10,055 in 2000 dollars per person.
 - Costs varied substantially by diagnostic group. If the person died during the waiting period, costs were estimated to be \$25,864; if the person recovered, costs were estimated to be \$1,506.²⁵² One study suggested that eliminating the 24-month Medicare waiting period would cost \$5.3 billion, while another study estimated the cost at \$8.7 billion. The reasons for differences in the estimates are the following:
 - The \$5.3 billion used 2000 dollars while the \$8.7 billion is in 2002 dollars.
 - The \$5.3 billion estimate is only for SSDI beneficiaries who qualified under their own work record, while the \$8.7 billion estimate includes adult offspring and surviving spouses of people with disabilities.
 - Each study used substantially different estimation methodologies. Neither of these estimates included the cost of the prescription drug benefit that started in January 2006.²⁵³
- When it was first created, the SSDI Program probably was effective in its legislative objective to replace a portion of income lost due to a qualifying disability. However, because of the many changes that have occurred since 1956, the program design does not optimally meet the needs of people with disabilities.
 - For example, advances in technology and legislation like ADA have opened the workplace and made it more accessible to all people.

- In addition, many disabilities that in the past might have been permanent, completely, or severely limiting may now be treatable and accommodated because of advances in medicine and technology. These changes have made some aspects of the current disability program outdated.
- The GAO expressed a similar conclusion when it recently placed all federal disability programs on its high-risk list. SSA is exploring how to reshape the SSDI Program in the future to reflect these changes and how to improve the processing of disability claims, which can be lengthy.²⁵⁴

2E:2 – Supplemental Security Income

SSI derives from many of the same premises as SSDI, but with several key differences. SSI extends the safety net to all people with disabilities regardless of age, and to all senior citizens regardless of disability, who meet its strict income- and resource-eligibility standards. SSI also differs from SSDI in being strictly means-tested, beyond the fact of the capacity for earnings. Unearned income is taken into account in determining eligibility and benefit amounts, as are savings, along with employment. Lastly, SSI differs from SSDI in being linked not to Medicare but to Medicaid, meaning that the state plays two important roles in it that are not paralleled with SSDI. These roles are that the state may or may not add a state supplement to the standard SSI payment (the federal benefit rate) and that the state, through its discretion in administering the Medicaid Program, will determine to a large degree exactly what health services an individual will receive. For people whose route to eligibility comes through disability rather than age, monitoring disability status as well as economic status is a standard component of the program.²⁵⁵

Findings

- The SSI Program is not, however, free of major design flaws, including the following:
 - The disability determination process does not ensure that the right people get benefits on a timely basis.

- The complex rules related to income and assets make it difficult to pay people the correct amount.
 - Many of the medical listings that are used as part of the disability determination process do not recognize advances in medicine that would enable individuals to work.
 - The vocational information used as part of the disability determination process is out of date.²⁵⁶
 - The GAO expressed a similar conclusion when it recently placed all federal disability programs on their high-risk list.
 - Despite the drawbacks in program design noted above, the SSI Program, with its nationally uniform standards and payment levels, is a considerable improvement over its predecessor programs.²⁵⁷
- The SSI Program does not always effectively reach its intended beneficiaries.²⁵⁸ In 2002, \$2.7 billion, or 8 percent, of all SSI payments were improper. There are inconsistencies across states and between Disability Determination Services (DDS) and Offices of Hearings and Appeals in decisions about whether someone is a person with a disability. A Lewin Group study has shown that within individual DDSs, examiners come to different decisions on the same types of cases.²⁵⁹
 - SSA is working to reduce inconsistency. SSA has developed both short-term and long-term strategies.
 - The short-term strategy includes early screening of hearings for on-the-record decisions, using a short form for fully favorable decisions, and deploying speech recognition and video teleconferencing technology to hearings offices.²⁶⁰
 - For the long term, the SSA commissioner has developed a new approach to disability determinations that focuses on making the right decision as early in the process as possible.²⁶¹ This approach is predicated on the successful implementation of SSA's new electronic disability system.

- The major findings of the 2005 *Annual Report of the Supplemental Security Income Program* are the following:²⁶²
 - By 2029, the end of the 25-year projection period, the federal SSI recipient population is estimated to reach 8.7 million.
 - The projected growth in the SSI Program over the 25-year period is largely due to the overall growth in the U.S. population.
 - The rate of participation is projected to vary somewhat by age group, with the overall participation of the age groups 65 or older projected to decline and the participation of the under-65 age groups projected to increase slightly.
 - The number of federal SSI recipients remained essentially level at 2.2 percent of the total U.S. population in 2004, and is projected to increase gradually to 2.4 percent of the population by 2029.
 - Federal expenditures for SSI payments in calendar year 2005 were estimated to increase by \$2.2 billion to \$36.4 billion, an increase of 6.4 percent from 2004 levels.
 - In constant 2005 dollars, federal expenditures for SSI payments are projected to increase to \$45.8 billion in 2029, a real increase of 1.1 percent per year.
 - When compared to the gross domestic product, federal SSI expenditures are projected to decline over time, from the current level of 0.29 percent of GDP in 2004 to 0.24 percent of GDP by 2029.

2E:3 – Ticket to Work and Work Incentives Improvement Act of 1999

Thousands of people with disabilities and their advocates shared enthusiasm that TWWIIA would greatly expand employment opportunities for people on the SSA disability rolls,²⁶³ providing an alternative to direct income maintenance for individuals with disabilities. Three years after enactment of the law, it is clear that TWWIIA is faltering. The Ticket to Work and Self-Sufficiency Program (Ticket Program) is failing to recruit the anticipated numbers of new employment service providers, called

Employment Networks (ENs). In addition, ENs are serving only a fraction of the beneficiaries thought to be interested in participating in the Ticket Program. Nearly 1,000 providers have enrolled in the program, but only about one-third of programs operating have accepted any tickets.²⁶⁴

Findings

- The SSA Ticket to Work Advisory Panel has urged Congress and the SSA commissioner to take quick action on the following issues:
 - Ticket Program as a supplemental funding source. ENs are uncertain about whether and how they can use funds from other public sources to serve ticket holders and have chosen not to actively participate in the Ticket Program because of fear of losing other stable funding sources.
 - EN payment system. Two problems in the EN payment system discourage the active participation of many providers:
 - The payment system places too much financial risk on ENs.
 - The payment system provides significantly lower reimbursements to ENs for serving SSI recipients than for serving SSDI beneficiaries.
 - Adequacy of provider incentives. Because little is known about outcome payments for providers, TWWIIA authorizes the SSA commissioner to review, refine, and alter the payment system to ensure that it provides adequate incentives for ENs to serve beneficiaries and produce savings to the program. Despite major problems with the payment model, no alterations have been made to the original program payment system. The commissioner has established an advisory group on adequacy of incentives to assist SSA with the design of a workable payment system, including financial incentives to serve four groups of beneficiaries with special needs that were referenced in the legislation.
 - EN payment claims administration. Two factors compound the financial risk and working capital problems of Employment Networks:

- Long-term tracking of beneficiary earnings is labor intensive and administratively burdensome for ENs.
- Often there are long delays in processing EN claims for payment.
- Marketing to ENs and to beneficiaries. To date, there is no national marketing plan for the Ticket Program, and the program is not well understood by the vast majority of beneficiaries or by people who influence a beneficiary's decision to attempt work. ENs spend considerable time explaining the program and dispelling misconceptions. In addition, the lack of marketing contributes to the insufficient demand for EN services. However, SSA has been awarded contracts to support development of a strategic marketing plan and EN marketing and recruitment efforts. The Ticket to Work Advisory Panel has made numerous recommendations to the commissioner on this issue in past reports.
- EN training and communication. Inadequate training, technical assistance (TA), and timely information is available to ENs. Existing TA and training resources are inadequate, nonuniform, piecemeal, uncoordinated, and of varying quality, with no coordinated means for ENs to identify and share best practices.²⁶⁵

2E:4 – Financial Incentives for Income Maintenance Work Better for Some Individuals with Disabilities than for Others

Work disability is a costly problem in the United States. In 1988, for example, the costs of work disability included \$22 billion in SSDI payments, \$11 billion in SSI payments to people who are blind and people who have other disabilities, \$19 billion in Medicaid expenditures, and \$27 billion (1987) in workers compensation payments (Employee Benefit Research Institute, 1990).²⁶⁶

Findings

- Marjorie L. Baldwin and William G. Johnson, in *Dispelling the Myths about Work Disability*, describe four principles (related to prevalence of disability types, onset of

disability, factors impacting employment outcomes, and wage differences) that contradict common misconceptions of disability and working:²⁶⁷

- The most frequent types of disabilities are not present at birth or are the result of traumatic accidents. Instead, they are musculoskeletal conditions, such as arthritis, or cardiovascular conditions, typically caused by chronic degenerative processes that increase as people age. Among younger age groups, mental illnesses form the most prevalent disability category.
- Most workers with disabilities did not have disabilities as children and were not, therefore, subject to discrimination in education or employment at the time of entry into the labor market.
- The ability of a person with a disability to work does not depend solely on the nature of his or her disability and the quality of medical care received. Many other factors, including characteristics of the worker and usual job, attitudes of employers, labor market conditions, and the availability of workplace accommodations, are important determinants of employment outcomes for workers with disabilities.
- There are large wage differentials between workers with and without disabilities that are not explained entirely by health-related differences in productivity. Although productivity differentials are one important factor explaining the wage differentials, employer discrimination also contributes to the low wage rates of workers with disabilities.
- People with Down syndrome and other people with significant disabilities depend largely upon SSI to augment their income, and upon Medicaid to pay for their health expenditures. Today, opportunities have increased for this population to show their capacity and desire to become productive contributors to their communities through meaningful employment. Both SSI and Medicaid, however, have caps so that when people with significant disabilities earn too much money or accumulate too many resources, they are no longer eligible for these programs.²⁶⁸ The job market for people with disabilities, although improving, is not stable. As a consequence, many people with significant disabilities²⁶⁹ choose not to work to their full capacity for fear

of losing their benefits. Adults with significant disabilities could earn no more than \$860 a month in gross wages in 2006 or they would lose their SSI eligibility. This cap prevents people with significant disabilities from pursuing and obtaining employment opportunities that would provide more financial independence. They are forced to remain in low-paying jobs under the current regulations. They can have no more than \$2,000 in total resources or they will lose their SSI eligibility.²⁷⁰ This fact prevents them from saving money or investing in a home of their own. Families cannot bequest or give resources in the name of an individual with significant disabilities, since most often these are counted toward the \$2,000 eligibility cap. Thus, the current regulations force adults with significant disabilities to remain in a state of poverty.²⁷¹

- A recommended solution is to subtract Impairment-Related Work Expenses (IRWE) after countable income is determined in SSI payment calculations. Individuals who are blind subtract their work-related expenses after countable income is determined. This means that they can reduce their countable income by twice as much as people with other disabilities. The smaller the countable income calculation, the larger the SSI benefit payment will be.²⁷²
- Advocates for patients with inflammatory bowel disease (IBD) believe that the SSA process for determining eligibility for disability insurance may treat some claimants unfairly.²⁷³ As a result of perceived unfair treatment regarding eligibility determination, claimants with IBD believe they are likely to be denied benefits at the initial decision and reconsideration levels, making it necessary for them to appeal to the SSA hearings level to have their claims allowed.
 - However, the GAO found that while claimants with IBD are somewhat less likely to be allowed SSDI benefits than claimants with other disabilities, their experiences applying for disability benefits are not unique, and SSA has efforts under way that may address some claimant concerns.
 - To help ensure that all claimants are informed of and provide SSA with information needed to assess fairly how disabilities limit claimants' ability to work,

the GAO recommends that SSA emphasize the types and importance of information claimants must submit for their claim.

- SSA agreed with the GAO's recommendations, but thought that some perspectives the GAO provided on evaluating IBD claims were not relevant, and that the GAO's characterization of one finding went too far.

2E:5 – Gaps in Access and Availability of Financial Incentives for Income Maintenance for Individuals with Disabilities Compared to Individuals without Disabilities

Median household income of (working-age) men without disabilities increased by 9.4 percent and median household income of women without disabilities increased by 12.6 percent between 1989, the peak year of the 1980s business cycle, and 2000, the peak year of the 1990s business cycle.²⁷⁴ In contrast, the median household income of men with disabilities fell by 2.9 percent and the median household income of women with disabilities fell by 5.6 percent over the period.²⁷⁵

Findings

- The proximate reason for the dramatic difference in the fortunes of the working-age population with and without disabilities was the dramatic divergence in their employment rates over the period.²⁷⁶
 - The employment rate of men without disabilities was “procyclical” (i.e., followed the business cycle), declining during the recession years of the early 1990s but then growing over the later recovery years.
 - In contrast, the employment rate of men with disabilities declined both over the recession years and over the recovery years of the 1990s.
 - The long-term growth in the employment rate of women muted some of the cyclical effects on their employment rate. The employment rate of women without disabilities rose during both the recession and recovery years but rose much more during the growth years. Women with disabilities experienced declines in

their employment rate over the entire period (despite the increase in median household income), although the decline was smaller over the growth years.

- The failure of the employment rates of both men and women with disabilities to increase during the growth years of the 1990s business cycle (after 1992) was a complete reversal of the procyclical behavior of their employment rates over the 1980s business cycle.
- The GAO found that lifetime earnings, the incidence of disability, and mortality are three key factors that influence the taxes individuals pay into the Social Security system and the benefits they receive.²⁷⁷ Lifetime earnings factor directly into the Social Security benefits formula, which is designed to replace a larger proportion of pre-retirement earnings for low-income earners than for higher-income earners. Additionally, the probability of being on the disability insurance rolls affects the expected value of benefits. People with disabilities start receiving benefits earlier. The third factor, mortality, affects the benefits received relative to taxes paid because it determines the number of years a person will pay taxes and receive benefits.²⁷⁸
- Differences by race in the relationship between taxes paid and benefits received under Social Security are due mainly to differences in lifetime earnings, the incidence of disability, and mortality among the groups.²⁷⁹ In the aggregate, African-Americans and Hispanics have higher disability rates and lower lifetime earnings, and thus as a group tend to receive greater benefits relative to taxes than whites. However, whites with low lifetime earnings or high disability rates also receive greater benefits relative to taxes than their higher-income counterparts or those without disabilities. Higher benefits relative to taxes paid are associated with lower lifetime earnings and higher disability incidence.²⁸⁰

2E:6 – Policy Changes to Expand Utilization of and Participation in Financial Incentives for Income Maintenance for Individuals with Disabilities

Findings

Structural weaknesses in the SSDI and SSI programs have prevented the agency from offering return-to-work services when they may help most—soon after a person becomes identified as having a disability.²⁸¹ Some federal programs other than SSDI and SSI also face the challenge of providing services in a timely fashion. For example, 38 percent of the programs that provide employment-related assistance to people with disabilities reported that ensuring timely provision of services and benefits was a challenge.²⁸²

- Similarly, despite the VA's recent progress in reducing its disability claims workload, it will be difficult for the agency to cope with future workload increases due to several factors, including increased demand for services linked to military conflicts and federal legislative mandates. Almost half the programs that provide employment-related assistance and 54 percent of the programs that provide medical care reported that planning for growth in the demand for assistance was a challenge.²⁸³
- The GAO recommends that the commissioner of Social Security develop a comprehensive strategic plan to ensure the reliability and usefulness of the data the agency collects. SSA should take the following steps to improve its data reliability and usefulness:²⁸⁴
 - Establish a cost-effective internal control strategy for ensuring the reliability of data in electronic disability records that would include both front-end controls on data entry and a tracking and feedback system for back-end verification of the electronic records.
 - Take steps to review the usefulness of the types of information collected and consider whether additional types of information could improve program oversight. This effort could include a survey of users of electronic disability data.

- In August 2004 and January 2005 the GAO found the following:²⁸⁵
 - SSA has made progress implementing and evaluating the Ticket Program, but the agency has had limited success in achieving the program's goals of expanding beneficiaries' choice of service providers and increasing beneficiaries' efforts to work and become self-sufficient. Although SSA experienced delays with the initial distribution of tickets, the agency finished distributing tickets to eligible beneficiaries throughout the nation in September 2004. As part of implementation, SSA also has contracted for extensive assessments of its program's performance. Despite SSA's completion of key implementation activities, it has had limited success achieving its goal to encourage service providers to join the program and provide services to beneficiaries.
 - The Ticket Program's ability to achieve its goals has been hindered by several factors, according to the Ticket to Work Advisory Panel,²⁸⁶ researchers, and service providers. First, service providers believe that the program's payment system does not provide adequate compensation for the administrative costs of participating. Second, participation of eligible beneficiaries has been limited by the lack of ENs, the lack of outreach to provide information about the program, and the lack of incentives to encourage beneficiaries to participate.
 - GAO also reported that the Ticket to Work Advisory Panel and others have suggested numerous changes to improve the Ticket Program. They believe that reforming the payment system is critical to expanding participation. In addition, they suggest numerous changes to reduce the administrative burden for service providers, such as having SSA provide additional services, guidance, and information to providers.²⁸⁷
 - SSA faces several challenges as it tries to improve the Ticket Program's ability to achieve its goals. Although SSA has made some administrative changes to the program, the agency recognizes that additional changes are needed. However, SSA has deferred other reforms until it has performed additional assessments on changes that it believes could be costly.

Asset Development

2E:7 – Demographic and Trend Characteristics of Asset Development Impact for People with Disabilities

Introduction

The field of asset development has emerged as the “third pillar” of social policy intended to complement income support from public benefits programs and social services for low-income Americans. Asset building for people with disabilities is viewed as a way to complement (not replace) income support and to foster income preservation from public and private benefits programs.

Assets have many possible meanings, but as a general concept, assets are rights or claims related to property, both tangible and intangible. Such rights or claims are enforced by cultural expectations and formal laws and regulations. Assets can be invested or otherwise made active to generate returns. Broadly conceived, assets can refer to anything that has this potential for positive returns. The research demonstrates that asset ownership is a good thing and that individuals who have assets live longer, are healthier, and have more education than individuals without assets. For the purpose of this research, assets are defined as capacities and resources that enable individuals with disabilities and their families to identify, choose, and implement activities that sustain and enhance their quality of life and improve their long-term economic, social, and psychological well-being. Assets can be separated into the following three categories that represent direct, indirect, and community-based incentives.²⁸⁸

- 1. Individual financial and nonfinancial assets:** money and savings; stocks, bonds, and other financial securities; real and personal property, machines, equipment, tools, assistive technology, durable household goods, and other components of production.
- 2. Human capital assets:** skills, knowledge, and experience gained from education and training.

3. Gateway assets: formal and informal community assets, cultural capital, and social capital that consist of the value of access to family and social contacts, education, transportation, communications, the political process, organizations, health care, and credit and expert advice (such as tax and financial advice).²⁸⁹

Findings

- Americans acquire assets through many channels besides work. Ownership of assets for many Americans often comes from sources other than income from work.²⁹⁰ The research on assets describes family of origin, geography/environment, education, ethnicity, class, inheritance, personality, and even legislation enacted more than a hundred years ago, such as the Homestead Act, as strong predictors of asset ownership in the 21st century.²⁹¹ More than 55 percent of people with disabilities are “asset poor” (live at the federal poverty level and have only enough resources for three months).²⁹²
- People with disabilities often are unemployed or under employed, or live with fixed or capped incomes. Examples are the three and a half million adults with disabilities receiving federal Supplemental Security Income (SSI) benefits equal to monthly incomes of \$512 in 2000.²⁹³
- The research shows that, fewer than 10 percent of individuals with intellectual disabilities and fewer than 50 percent of individuals with disabilities are home owners. In reality, many low-income Americans survive through substantial help from families, hard work, their community and religious affiliations, and income support and social services from the government and private charities.²⁹⁴
- Americans with disabilities represent one-third of American families (29 million out of 72 million families) and are likely to be twice as likely to be poor compared to their neighbors without disabilities.²⁹⁵ Individuals with disabilities who are poor represent almost 18 percent of the Americans age 5 and older; among Americans age 5 and older without disabilities, individuals who are poor comprise 11 percent of the population. Twenty-five percent of American children with disabilities (ages 5 to 15) live in poverty, compared to 15.7 percent of children without disabilities. Americans

with disabilities between the ages of 16 and 64 make up the next largest number of people living in poverty, at 19 percent—nearly double the rate of individuals in the same age range without disabilities.

- Americans who live in the South are more likely to be poor and have a disability than people living in other locations in the United States. Disability prevalence is higher in the South, with two out of every five living with a disability; in the other three regions of the United States, one in five live with a disability.²⁹⁶
- American employment opportunities favor individuals without disabilities. Seventy-nine percent of working-age men between the ages of 16 and 64 are employed, compared to 60.1 percent of working age men with a disability. Working-age women without disabilities experience employment rates of 67.3 percent, compared to 51.4 percent for their colleagues with disabilities. The employment rates for people with disabilities who were heads of families were 53.3 percent, compared with 80.7 percent of all people who were heads of families.
- Families with members with a disability had a median income of \$39,155 compared with the overall family median income of \$50,046 for families without members with disabilities. For example, families with members with mental disabilities had median incomes of \$36,197, and families with members with a sensory or physical disability had median incomes of \$36,950.²⁹⁷ In 1999, among families that had members with a disability, 73.1 percent of the families had earnings from wages or salaries, compared to 84.9 percent of families without members with disabilities. Families with members with disabilities were more likely to receive income from public programs (42.8 percent of the families that had members with a disability received income from Social Security compared to 22.5 percent of families without members with disabilities).
- Global demographic changes will impact disability policy in the United States. The world's population quadrupled in the 20th century and is predicted to grow by 50 percent by the end of the 21st century.²⁹⁸ Life expectancy in the United States has increased 30 years in less than a hundred years, with the fastest growing age group now in their 80s. Life expectancy for people with disabilities has increased as well,

and the population of individuals with disabilities under age 65 has increased 25 percent. The future economics of the country is uncertain and is projected to challenge the social system of spending entitlements for individuals with disabilities, approaching \$300 billion for 2005.

- Americans from diverse racial and ethnic backgrounds have a higher prevalence of poverty and disability than the general population. American Indian and Alaska Native householders made up 38.5 percent; for African-American householders the prevalence rate was 35.7 percent; for non-Hispanic white householders the prevalence rate of disability was 27.1 percent; for Asian householders the prevalence rate was 26.5 percent; and for Hispanic families the prevalence rate of disability was 33.2 percent reporting one or more members with a disability.²⁹⁹ Some people with disabilities who have low incomes have more barriers^{300,301} than other people to achieving home ownership or accumulating assets.
- Realizing the American dream of home ownership and economic self-sufficiency has not been a reality for most working low-income Americans. Outcome data from the American Dream Demonstration, which studied the savings behavior and use of financial instruments and services of thousands of low-income working Americans, did not include account holders with disabilities.³⁰²

2E:7A — Utilization of Tax and Financial Services

Historically, when the tax code was written and federal disability policy, such as Medicaid and Supplemental Security Disability Insurance, was drafted, there was no thought that asset development would ever apply to individuals with disabilities, who were mostly hidden from society and not in the mainstream workforce. The overarching notion of disability as limitation and need was the norm, with poverty as its most outstanding asset well into the second half of the 20th century. Steven Mendelsohn, a noted attorney and disability tax expert, found that even today the word *disability* appears most frequently with the word *death* in the Internal Revenue Code and noted that “Americans should be embarrassed at reinforcing these associations and recognize

the ongoing harm they do to the contemporary efforts to bring people with disabilities in to mainstream American life.”³⁰³

Despite the progress made over the past 50 years in advancing the rights of individuals with disabilities to be educated, to work, and to live independently, much progress is still needed. Working Americans with disabilities are three times as likely to be in poverty as their colleagues without disabilities. For Americans with disabilities to take ownership of their futures, the following key factors need to be addressed:

- Chronic poverty that promotes exclusion and limits participation in mainstream American life
- Unemployment and underemployment due to the lack of meaningful education and training for jobs beyond entry level
- High school dropout rates that are highest for young men with disabilities
- Lack of access to affordable long-term services and supports for everyday living and work
- Absence of health care providers who understand disability and its medical components
- Lack of housing that is accessible and affordable
- Lack of transportation that is accessible, reliable, affordable, and central to where people with disabilities live
- Lack of community integration, evidenced by the high prevalence of loneliness and isolation experienced by individuals with disabilities
- Outdated disability policy that discourages work and savings
- Lack of knowledge about the relationship of public benefits to earned income and to savings opportunities, such as matched savings accounts and the Earned Income Tax Credit

The enduring nature of these chronic conditions results in obstacles to building income preservation and self-sufficiency for Americans with disabilities.

Findings

- Financial institutions have conducted and reported little research on the financial service needs, use, and activities of individuals with disabilities. Historically, the banking industry has paid little attention to disability as a market segment. The ways in which individuals with disabilities manage their finances (checking and savings accounts), plan for retirement, make investments, and do their everyday banking are unstudied.³⁰⁴ In addition, little information is known about the accessibility of various financial services except for the recent evolution of voice-activated ATMs, which for the first time in history made banking privacy and independence available to millions of Americans who are blind.³⁰⁵
- The National Federation of Community Development Credit Unions has developed a national work committee with aggressive disability outreach in order to bring disability awareness and financial services and disability education to its national network of more than 230 credit unions.³⁰⁶
- The tax filing behavior and use of the IRS free tax services by individuals with disabilities is unstudied. Historically, the IRS has not collected data on individuals with disabilities and their utilization of and access to a wide array of free tax preparation services, which include walk-in clinics, 800 numbers, and Web sites.
- Americans with disabilities underutilize tax provisions. The National Organization on Disability (NOD)/Harris survey found that 83 percent of people with disabilities never claimed available tax credits and or deductions related to work.³⁰⁷ Less than half of people with disabilities who own homes claim the home mortgage interest deduction, often because of their low income, failure to itemize, and lack of knowledge.
- The EITC is a true asset-building opportunity that is underutilized by working individuals with disabilities on public benefits. A Ford study that examined the needs

of taxpayers with disabilities found that only 25 percent filed for the EITC and that few understood the benefits of filing taxes even when not required to by law.

2F – Housing

Introduction

Being part of the community and living as independently as possible are among the most important values and goals shared by disability advocates and people with disabilities and their families. A home of one's own—whether rented or purchased—is the cornerstone of independence for people with disabilities. However, across the nation, people with disabilities face a crisis in the availability of decent, safe, affordable, and accessible housing. Today, many people with disabilities still live in large, congregate facilities or other inappropriate places such as institutions. Approximately 750,000 people with developmental disabilities live with aging parents (one of whom is over age 65).³⁰⁸ For people who use wheelchairs or other mobility devices, finding housing with even basic accessibility features (e.g., an entrance with no steps) ranges from daunting to impossible. This difficulty is magnified in rural areas where there is a scarcity of any rental housing and new units rarely are developed. In addition, the designation “for elders only” of almost half a million units of Department of Housing and Urban Development (HUD)-funded public and assisted housing over the past 12 years has had a devastating impact on people with disabilities.³⁰⁹

Purpose and Method

The purpose of this section is to examine the evidence-based practices that demonstrate the impact of housing financial incentives on the daily lives of individuals with disabilities. The research will include direct, indirect, and community-based impacts of housing financial incentives. The examination will address whether housing financial incentives work better for some individuals with disabilities than for others; the gaps in access and availability of housing financial incentives for individuals with disabilities compared to individuals without disabilities; and what policy changes are needed to expand utilization of and participation in housing financial incentives for individuals with

disabilities. The findings from this section will be used in chapter 4 to inform the recommendations for reform that will include a framework for congressional, legislative, and executive-level involvement.

2F:1 – Discrimination against Home Seekers with Disabilities

Overcoming the preconceptions of service providers and housing professionals regarding the capabilities of people with disabilities has been a challenge. Often, service providers are accustomed to promoting supported living programs as the best option for people with disabilities. In addition, housing agency professionals often have fears and misconceptions that make them hesitate to work with people with disabilities.³¹⁰

Similarly, with respect to the well-established and better-known criteria for physical accessibility, grounds exist for concern over whether the value to people with disabilities is being maximized regarding the housing subsidies in question. Without attention to needs-based program limitations on the ability of potential purchasers to aggregate down payments or meet even subsidized mortgage commitments, and without attention to integration of key infrastructural elements such as transportation, accessible commercial facilities, health care, or other community-based resources, use of subsidies may be limited. Faced with a perceived lack of coordination among housing, transportation, economic development, and health care planners and programs, a possible question is whether the number of individuals with disabilities who can benefit from these subsidies is as large as it might be.

Findings

In June 1999 the U.S. Supreme Court in the *Olmstead v. L.C.* decision made it clear that ADA protects people with disabilities from being confined unnecessarily in restrictive settings such as nursing homes or institutions.³¹¹ The ADA “integration mandate,” with the support of President George W. Bush and his Administration, requires each state to develop “comprehensive effective working plans” to expand the availability of housing and other community-based supports. Such planning efforts must

respond to the needs of individuals with disabilities both at risk of as well as living in public institutions and nursing homes.³¹²

In *Discrimination against Persons with Disabilities: Barriers at Every Step*, researchers from The Urban Institute of Washington, DC, found widespread discrimination against individuals with disabilities seeking rental property.³¹³ The report states, “Deaf testers seeking rental housing were significantly less likely to be able to speak to a housing provider than were their hearing counterparts about available units.”³¹⁴

In addition, the study found that “16 percent of rental housing providers who indicated that they had units available for the wheelchair user refused to make or allow for reasonable unit modifications, and about 19 percent of people who had on-site parking refused to make the reasonable accommodation of providing a designated accessible parking space.”³¹⁵ The researchers also found that wheelchair users experience significant levels of adverse treatment with respect to housing availability. In 5 percent of tests, the rental housing provider told the tester without an obvious disability that a unit was available while telling the tester with a disability that no units were available.³¹⁶

Nationwide, over 4 million individuals with disabilities depend on SSI as their sole source of income (\$552/month, 2003), pricing them out of housing markets. Since 1992, Congress has authorized housing agencies to exclude people with disabilities from certain properties designated as housing for elders only, resulting in a loss of over 300,000 units nationwide. Federal budget authority almost doubled from 1976 to 2002 (\$1.2 trillion to \$2.1 trillion), while HUD budget authority declined by 41 percent. In many local communities, housing subsidies (rental vouchers) go unused because of escalating rental rates and landlord disinterest.³¹⁷

In a 2004 report funded by the HHS Center for Mental Health Services/Substance Abuse and Mental Health Services Administration (CMHS/SAMHSA) Bazelon Center for Mental Health Law researchers found that the rental market has been unresponsive to the needs of home seekers with psychiatric disabilities ever since the advent of deinstitutionalization in the 1960s.³¹⁸ The report claims that “In many states, people with

mental disabilities have been, and continue to be restricted to the least attractive parts of a community—to neighborhoods where housing often is relatively inexpensive and unsafe.”³¹⁹

The report also contends that little has changed in the “not in my back yard” (NIMBY) attitude.³²⁰ It states that the privatization of mental health housing has had effects that “will not be easily rectified without a major infusion of federal and state funding and an overhaul in the way states regulate these homes and coordinate agencies involved in human services delivery.”³²¹

For people with disabilities, discrimination plays a significant if unspecified role in obtaining housing. Every two years, the Technical Assistance Collaborative (TAC) and the Consortium for Citizens with Disabilities (CCD) Housing Task Force publish a study comparing SSI incomes with fair market rents. What TAC found in the latest study was the housing crisis for people with disabilities receiving SSI is worse than ever.³²² People with disabilities receiving SSI have extremely low incomes. SSI as income equals just 18 percent of median income, nationally. A person receiving SSI will need to pay 105 percent of his or her income to afford a modest one-bedroom apartment. Therefore, there clearly is a need for some type of government services. For a studio apartment, the news is not much better: a person receiving SSI would need to pay 89 percent of his or her income.³²³ In some urban areas, where rents are extremely high, it is even worse. In some rural areas the situation is not as bad, but housing still is not affordable.³²⁴

The 2002 National Cooperative Bank study³²⁵ found not one housing market in the country where a person receiving SSI could rent an apartment affordably. “Affordably” means that a person pays 30 percent of his or her income on rent and utilities. The income that SSI provides is equal to a wage of approximately \$3.43 an hour. The researchers also found that rent rose twice as fast as the SSI cost of living. The bottom line is the only way a person with a disability can bridge this affordability gap is to access housing subsidies.³²⁶

2F:2 – HUD Programs

There are two types of federal affordable housing programs. The first are housing subsidy programs that provide rent or operating support to a project or apartment that typically allows the tenant to pay between 30 to 40 percent of income on rent. The second are capital programs that provide resources to help fund capital development of affordable multifamily rental projects. Some of these programs provide either subsidy or capital funding. Capital programs include programs covered under the consolidated plan requirements of HUD. These programs provide block grants to states and Local Housing Authorities through the HOME Program, the Community Development Block Grant Program, the Housing Opportunities for Persons with AIDS Program, and the Emergency Shelter Grants Program. An additional capital program is the Low-Income Housing Tax Credit Program. It provides tax credits that developers can use to raise equity to fund the development of affordable rental housing.³²⁷

Findings

- The largest housing program, Housing Choice Voucher Program—a Section 8 program—is funded at approximately \$800 million a year and administered by 2,600 Public Housing Agencies (PHAs) nationally. The program is available in every locality from either a state, regional, or local PHA. It provides participants with a rent subsidy to identify a house in the local market. The subsidy amount is based on the household's income and the cost of housing in the local market. Typically, the participant will pay between 30 and 40 percent of income on rent. The PHA will pay the difference between the established rent and the tenant's rent share.³²⁸
 - During the past few years, many PHAs have had a poor success rate in using their vouchers. HUD has implemented a policy pushing PHAs to use it or lose it. This gives the federal entity an opportunity to partner with PHAs, because they are looking for eligible people to use these subsidies. In addition, PHAs that do not have a high utilization rate, defined as 97 percent or greater, are not eligible to apply for new vouchers. The utilization rate is the percentage of vouchers that the PHAs have under lease.³²⁹

- Since 1997, HUD has issued more than 60,000 new vouchers, which are targeted to people with and without disabilities within programs managed at the state or local level. More than 470 PHAs throughout the country have targeted the disability vouchers.³³⁰
- To the extent that fair housing laws are vigorously enforced, including through the levying of maximum fines for their violation, fair housing laws can represent a financial incentive to people with disabilities. Faced with a real risk of incurring costs for violating the law, building designers, owners, rental agents, and others are less likely to engage in discriminatory practices. In turn, the supply of available housing is be expanded, hence bringing down the price.³³¹
- Virtually all adults with disabilities receiving SSI benefits who do not have government housing assistance qualify under federal guidelines as households with “worst case” housing needs. Worst case housing needs are defined as the need to pay more than 50 percent of income for housing costs, or the need to live in severely substandard housing. A 1996 HUD report indicates that people with disabilities are more likely than elders or family households to experience both these housing problems.³³²
- The information in *Priced Out* in 1998³³³ is directed at federal housing policymakers and the nation’s affordable housing officials. During the early 1990s, the Federal Government made no effort to assess accurately the housing needs of people with disabilities. Recent estimates have been more realistic, including numbers in a 1999 HUD report which documented that 25 percent of the 5.4 million households in the United States with worst case housing needs—approximately 1.4 million households—were people with disabilities.³³⁴ Statistics published by HUD in March 1998 document that people with disabilities assisted through HUD programs have an average annual income that is about 20 percent less than the income of elderly households receiving HUD assistance.³³⁵
- Section 8 of the U.S. Housing Act of 1937 (42 U.S.C. 1437f) authorizes housing assistance to aid families with low income in renting safe and decent housing. Housing assistance payments are limited by fair market rents (FMRs) established by

HUD for different areas. In the Housing Choice Voucher Program, the FMR is the basis for determining the “payment standard amount” used to calculate the maximum monthly subsidy for an assisted family.³³⁶ In general, the FMR for an area is the amount that would be needed to pay the gross rent (shelter rent plus utilities) of privately owned, decent, and safe rental housing of a modest (nonluxury) nature with suitable amenities. In addition, all rents subsidized under the Housing Choice Voucher Program must meet reasonable rent standards.

- To a limited extent, federal housing subsidies still include some rental subsidies that allow people with low income, and in some cases expressly allow people with low income who have disabilities, to pay for rental housing that they could not otherwise afford. The role of such subsidy and voucher programs has steadily declined.³³⁷ Even when such programs were a more prominent component of national housing policy, and to the extent that they remain in use in conjunction with other programs,³³⁸ recognition of the issues facing people with disabilities appears to have focused on only one dimension of access. That is to say, while economic eligibility standards recognize the limited income and resources of many people with disabilities, there has never been in the Section 8 (or Section 811) program any recognition that factors other than income, age, or family size need to be taken into account in determining the amount of subsidy or the kind of housing that would be appropriate. Thus, these programs have not included sufficient elasticity to reflect possible needs for additional space, or the heightened costs imposed on affordability by the scarcity of accessible dwellings.³³⁹ It seems likely that the value of direct financial incentives, or of indirect incentives, has been significantly undermined or limited by this failure.
- While it is clear that people with disabilities are represented among people with low income, whose access to housing has been enhanced by this financial incentive to a third party, nothing in the law itself rewards developers for designing or building in ways that would make facilities more accessible than what the law minimally requires. Many approaches could be fashioned that, consistent with well-understood

precepts of tax administration, would encourage accessibility and heightened outreach to people with disabilities.

2F:3 – The Role of Medicaid and Social Security in Combining Housing and Supportive Services for Individuals with Disabilities

In response to the increasingly higher costs of nursing facility care and the institutional bias that was part of the initial authority, home health services in 1970 became a mandatory federal benefit.³⁴⁰ In 1981, Congress authorized the Home and Community-Based Services waiver authority.³⁴¹ The Section 1915(c) waivers, named after the section in the Social Security Act that authorized them, allows states to provide services, not usually covered by the Medicaid Program, to keep a person from being institutionalized. Home and Community-Based Services (other than room and board) for specific defined eligible populations are now part of waiver programs in all 50 states.

In addition to the HCBS waiver authority, there is a Section 1115 waiver authority. Section 1115 of the Social Security Act provides CMS broad authority to support experimental, pilot, or demonstration projects to test new ideas related to the financing and delivery of medical and supportive services.³⁴²

2F:4 – Limited Equity Cooperatives

Limited equity cooperatives (LECs) are an option for populations that require an alternative to home ownership or renting. Cooperative housing can create a sense of community without the negative impacts of institutionalization or group living.³⁴³

Findings

- In a report by the City University of New York Graduate Center, the following criteria were found to be necessary for the success of LECs:³⁴⁴
 1. Sponsoring organizations, financial institutions, and regulatory bodies must develop offering plans, purchase and maintenance terms, and governance and

taxation structures that make the LEC investment a prudent one for low-income families.

2. Conveying property in good condition is essential. When this is not feasible, property should be conveyed only to residents who want to purchase and are prepared to make the necessary sacrifices.
3. Shareholder education and leadership development training are critical and must continue throughout the life of a LEC.
4. The specific housing market and economic conditions of an area dictate different regulatory and financing arrangements.

- In one study in New York City that surveyed 3,000 residents, LECs were found to be the most “reasonable” in cost when quality of housing was considered. Among co-op members, 7 out of 10 members found their monthly costs to be “very reasonable.” LECs scored highest on ratings of “repair quality and management characteristics, including quickness, durability quality information, availability and employees.”³⁴⁵

2F:5 – Ownership Programs

The programs that today chiefly characterize federal housing policy, as described in detail in several NCD reports over the past five years,³⁴⁶ emphasize home ownership as the primary goal of federal involvement, and as the primary measure of policy success. These programs take two basic forms. They include programs, many administered under Section 202, for the construction or renovation of housing that is then made available to appropriate buyers under variously subsidized conditions. In some cases the programs also involve direct subsidies or rent-to-own demonstrations. For many people with disabilities, a lack of financial resources, restrictive social service policies, and accessibility needs put home ownership out of reach.

Findings

- The HomeChoice initiative, a program recently developed by the Federal National Mortgage Association (Fannie Mae), is intended to help individuals with disabilities overcome these obstacles and achieve dreams of owning a home. HomeChoice has made grants of \$50 million over three years to 11 states and the District of Columbia.³⁴⁷
 - HomeChoice is an experimental mortgage product using modified lending standards developed specifically for the initiative. Borrowers who are eligible for the program are people with disabilities, including individuals who have court-appointed guardians and families who have a member with a disability living with them.³⁴⁸
 - Alabama, California, the District of Columbia, Massachusetts, Michigan, Minnesota, Missouri, New Mexico, New York, Oregon, Washington, and Texas received grants from Fannie Mae for HomeChoice projects. Each has created its own policies and procedures, and has structured its program somewhat differently. Some focus on serving particular disability communities, and certain programs provide only financing for home renovation—not new construction projects.³⁴⁹
 - Common to each project, however, is the involvement of a coalition of representatives of the housing and social service fields, and from the public, private, and nonprofit sectors. The coalitions pool their resources to help borrowers obtain financial assistance for down payments, closing costs, and accessibility or general repairs; they also provide foreclosure prevention help and any necessary social services. In addition, each program provides home ownership education and counseling to prepare borrowers for the responsibility of owning a home.³⁵⁰

2F:6 – Policy Changes to Expand Utilization of and Participation in Housing Financial Incentives for Individuals with Disabilities

Findings

- Many people with severe disabilities require supports or units with a higher degree of physical accessibility than is available in the private market. By limiting Section 811 funding solely to tenant-based vouchers, the Administration proposes a major change in the targeting of the Section 811 Program—away from people with severe disabilities, who have the most significant housing needs. This proposal will relegate these individuals to institutions, nursing homes, or homeless shelters.³⁵¹
- At a disability policy seminar in 2005 titled “Housing for People with Disabilities: The Crisis,” participants included The Arc, the American Association on Mental Retardation (now the American Association on Intellectual and Developmental Disabilities), the Association of University Centers on Disabilities, United Cerebral Palsy, and the National Association of Councils on Developmental Disabilities. Participants proposed encouraging Congress to increase Section 811 funding by at least \$129 million in FY 2006 to restore the program to its FY 2004 funding level and to require HUD to reinstate the capital advance/production component of the program.³⁵²
 - In addition, participants examined the Administration’s FY 2006 budget requests: a total of \$15.9 billion for the Section 8 Housing Choice Voucher Program, \$14.1 billion of which is for voucher renewals. No funding is proposed for new/incremental vouchers targeted to people with disabilities. This request will fund approximately 2 million vouchers—only 94 percent of the vouchers currently administered by PHAs. Full funding would allow PHAs to use all vouchers authorized by Congress. Prior to FY 2004, Congress fully funded all vouchers, including (from 1997 to 2001) vouchers targeted to people with disabilities. Since 2004, PHAs have not had sufficient funding to use all of their authorized vouchers.³⁵³

- The seminar group made the following recommendations to Congress:
 1. Increase funding for the Section 811 Supportive Housing for Persons with Disabilities Program by at least \$129 million to restore the program to its FY 2004 level (\$249 million) and require HUD to reinstate the program's capital advance/production component.
 2. Ensure that the Housing Choice Voucher Program is adequately funded so that current Section 8 voucher holders will retain their vouchers.
 3. Oppose any proposals that would block-grant the Section 8 Housing Choice Voucher Program.
- Ann O'Hara and Emily Miller, in their study *Going It Alone: The Struggle to Expand Housing Opportunities for People with Disabilities*, report their findings³⁵⁴ about needs pertaining to state and local funding priorities, PHAs, information sharing on federal housing programs, home ownership, and expanding access to affordable housing. Among the findings are the following points:
 - State and local housing officials do not give a high priority to the housing needs of people with disabilities. Only 10 percent of state/local housing officials, 18 percent of PHAs, and 26 percent of state/local housing finance agencies have made housing for people with disabilities a high priority for funding in their communities.³⁵⁵
 - Most PHAs are not working with the disability community to expand housing options. HUD data indicate that only 10 percent of all PHAs collaborated with the disability community each year to seek new Section 8 vouchers for people with disabilities.³⁵⁶ In addition, the HUD data showed the following:
 - Most disability organizations have not established relationships or partnerships with affordable housing providers and funders. Only 16 percent of home ownership coalitions and only 22 percent of CCD members and affiliates had formed partnerships with PHAs to expand access to Section 8

vouchers. On a more positive note, 48 percent of home ownership coalitions serving people with disabilities had formed partnerships with government and nonprofit housing agencies—progress that should eventually improve the outcomes of HomeChoice and Home of Your Own coalitions.

- The disability community's knowledge of key federal housing programs and policies that can assist people with disabilities is very limited. Only 14 percent of CCD members and affiliates have an understanding of HUD regulations, only 19 percent know about the PHA Plan and its impact on the Section 8 Program, and only 41 percent know that Section 8 rent subsidies can be used to expand home ownership as well as rental housing opportunities. On a more positive note, 62 percent of CCD members and affiliates know that new Section 8 vouchers are available to help people with disabilities.
- The disability community has very limited knowledge of Fannie Mae housing programs targeted to people with disabilities. Most organizations were not aware of the full array of Fannie Mae products available to assist people with disabilities, including HomeChoice, Community Living Program, and Retrofitting Mortgage. In fact, only 9 percent knew about all three products: 27 percent knew only about HomeChoice, 3 percent knew only about the Community Living Program, and 2 percent knew only about the Retrofitting Mortgage.
- Many disability organizations do not understand how participation in HUD's Consolidated Plan process can help expand home ownership and rental housing for people with disabilities. At the time of the survey, only two home ownership coalitions had assisted 60 or more households with disabilities to purchase a home. Both these coalitions have the active participation of state and local housing officials, housing counseling agencies, and private lenders in the coalition model. The majority of coalitions had assisted fewer than 30 households, and two were just getting started and working to help their first household.

- Most home ownership coalitions serving people with disabilities have achieved only modest results in terms of the number of people who have become homeowners.
- With more housing knowledge, capacity, and technical assistance, disability organizations can help expand access to affordable housing. Of the 21 disability organizations that had learned how to apply for HOME or Community Development Block Grant funds, 14 reported success—a 67 percent success rate. A similar rate (56 percent) was achieved by disability organizations seeking Federal Home Loan Bank Affordable Housing Program funds for down payment assistance or rental housing production. This finding underscores the future potential for better housing outcomes from within the disability community, provided their housing knowledge and capacity issues can be addressed.³⁵⁷

2.3. Conclusion

Chapter 2 has presented an overview of findings from the literature and analyzed the state of current research and the impact on existing federal programs to promote enhanced independence and community participation for people with disabilities through direct and indirect financial incentives. The review of the literature on what is working and changes that are needed to advance self-sufficiency for the target population sets the stage for the design of a 21st century policy framework that maximizes the use of financial incentives to promote changes in behavior at individual, family, and community levels.

What is perhaps most striking is the paucity of evidence-based research on cost-benefit calculations, which would justify continuation of progressive public policies and the improvement and adjustment of other public policies that serve as barriers to the advancement of social and economic inclusion in mainstream community life for individuals with disabilities and their families. Little effort, if any, has been focused on analyzing and calculating the benefit of indirect financial incentives that make communities more livable for everyone. The intersection of universal design of housing,

education, transportation, employment, and technology access and use that would benefit people with and without disabilities in a “livable community” is not yet a focus of evidence-based research design. Little is understood of costs saved in individual social programs as a result of the livable community construct, and even less is known about the cost-benefit ratio for people with disabilities.

Finally, the new tools and strategies of the past 20 years, such as the EITC, IDAs, and financial education, developed by Congress to help workers with low incomes, are just beginning to be marketed through outreach to people with disabilities.

The results describe financial disincentives and other federal tax and social policies that are inconsistent with the principles of ADA and the focus of this study. To improve economic status and community participation for people with disabilities, all existing policy levels must be evaluated based on the preferred valued outcomes of independence, inclusion, and the advancement of economic freedom.

Chapter 3: Research of Promising State Innovations

Introduction

In creating a 21st century framework for federal authorized direct and indirect financial incentives to positively impact people with disabilities and their families, it also is important to examine innovations that are being implemented by state governments. States in the past 10 years have become important originators of social policy reforms that respond to challenges related to affordable housing, welfare and work, access to health care, and transportation. The purpose of this chapter is to identify, document, and assess selected promising state innovations in policy design and implementation of direct and indirect financial incentives that are contributing to improved social and economic participation in community life for individuals with disabilities and their families.

Each state-authorized program was selected according to four criteria: (1) each of the selected state initiatives was authorized by the state legislature and as a result has a clear statutory authority; (2) each state program shows potential for replication by other states and at a federal level; (3) the selected program responds to a different element of the challenges to facilitate a more advanced social and economic status for individuals with disabilities and their families; and (4) each selected state has adopted policy that may exist in other states. However, the six states that were selected have program elements that are unique in terms of public and private participation and the leveraging of resources to compound the benefits to the individual and family, the community, and the state.

Table 1 identifies the six selected states—Louisiana, Missouri, Wisconsin, Maryland, Kentucky, and Washington—the program area, legislative authority, administering agency, year of implementation, and types of incentives.

Table 1: Study States

State	Program	Legislation	Administering Agency	Year Enacted	Type of Incentive
Louisiana	Education Student Tuition Assistance and Revenue Trust (START) Savings Program	S.B. 690 Act 332 S.B. 271 P.L. 174-1997	Louisiana Tuition Trust Authority (LATTA)	1995	Direct
Missouri	Long-Term Services and Supports Assistive Technology Program	S.B. 721 P.L. 191-862	Missouri Assistive Technology (MoAT) Council	2000	Direct
Wisconsin	Employment Medicaid Buy-In Program, also called: Medicaid Purchase Plan (MAPP)	Act 9 (1997) A.B. 152	Wisconsin Medicaid	2000	Direct
Maryland	Transportation Statewide Special Transportation Assistance Program (SSTAP)	H.B. 758 P.L. 106-417	Maryland Mass Transit Administration (MTA)	2001	Indirect/Community Based
Kentucky	Housing Universal Design Program	H.B. 289 H.B. 382	Kentucky Housing Corporation (KHC)	1993	Indirect
Washington	Asset Development Individual Development Accounts	S.B. 5469 WAC 388-470-0045	Office of Trade and Economic Development (OTED)	2000	Direct

All the state programs explained in this chapter have the potential for expansion and replication to better address each of the life domains of individuals with disabilities.

More detailed information about each state innovation is available via the NCD Web site: www.ncd.gov. An overview of each program is presented here.

3.1. Louisiana State Innovation

Louisiana's Student Tuition Assistance and Revenue Trust (START) Savings Program encourages families to save for the postsecondary education of their children and grandchildren. Parents, grandparents, and legal guardians may establish a college savings account to benefit their child or grandchild.³⁵⁸ The feature that makes the START Savings Program unique among savings plans is that, for the average family that has less than \$100,000 in annual income, the State of Louisiana will award an incentive to save by matching a percentage of the family's annual deposits. Deposits into individual accounts are pooled, invested, and professionally managed by the state treasurer.³⁵⁹ This is an important gateway to an education for individuals with disabilities, whose finances often are stretched to cover additional health care costs.

The problem for many Americans is that escalating tuition costs make it increasingly difficult to access a college education. Over the past 10 years, the price of a year of college at a four-year public institution has increased 36 percent—10.5 percent in 2006 alone.³⁶⁰ Affording these costs is especially challenging for families with few resources. Many individuals with disabilities and their families are forced to redirect resources to health care and other supports. Programs like START can provide a vehicle to finance college for people with disabilities who might otherwise be priced out of higher education.

Obtaining a postsecondary education usually is not only a necessary step in securing a well-paying job, but often is a vital step in achieving security, acquiring assets, and building wealth. For example, college graduates are more likely to have jobs with benefits, such as health insurance and retirement plans—two key pillars of economic well-being.³⁶¹ Therefore, financial access to higher education is crucial in enabling

people with disabilities to gain independence. Louisiana has led the nation in access to higher education by offering matching funds for its 529 Plans, and by promoting inclusion of beneficiaries who most need tuition assistance. Other states can greatly assist their residents with disabilities through a similar approach to college savings. The matched savings features of the program also could be adopted at a national level.

3.2. Missouri State Innovation

Missouri has a well-developed and well-funded assistive technology program as part of its long-term services and supports initiative for individuals with disabilities. The program includes ongoing training and accountability aspects, as well as the supports and services. The cost of the program is spread to all users of communicative devices through a tax to general phone services to cover the training, maintenance, and hardware to make the assistive technology program effective.³⁶²

Missouri has developed a complex network of loan programs and standards for entities accepting state funds to support full access to assistive technology for individuals with disabilities. On a national level, the expanded role of state Public Service Commissions could be authorized with adoption of the broader mandate to promote telecommunications and Internet access with appropriate products and services. The linkages to the entity in each state authorized by the federal Assistive Technology Act and the state Public Service Commissions also merit further exploration of ways to enhance the social and economic freedom of individuals with disabilities.

3.3. Wisconsin State Innovation

Wisconsin's Medicaid Buy-In Program differs from other states' plans in that Wisconsin provides an incentive for continued work effort by providing Medicaid Buy-In Program coverage during temporary periods of unemployment and before an individual finds a job as well. Wisconsin calculates separate payment obligations for earned and unearned income, with proportionately smaller premiums assessed on income derived from work. The fear of losing Medicaid coverage makes many people with disabilities

reluctant to find employment, despite the greater financial security it may offer them. Wisconsin's program allows individuals to work and keep their health care, which has led to a large number of participants' enrolling in the program.

The primary strategies available to control costs within a Medicaid Buy-In Program are the following:³⁶³

1. Limit enrollment to people with higher levels of earnings.
2. Establish an unearned income limit.
3. Impose premiums or other cost sharing.

Many states, Wisconsin included, have been actively developing programs to promote competitive employment for people with disabilities. Buy-In programs (enabling people with disabilities who have increased earned income to obtain Medicaid eligibility) have become a key component of state efforts. States are implementing Buy-In programs (and related programs and supports) not as welfare programs, but as programs that help states make productive use of all their human capital resources. Many policymakers support Buy-In programs as a means to increase the participation of workers with disabilities as productive citizens of states. Such programs are seen as a means to "enhance a state's economic status; not simply as a means to enhance access to health care."³⁶⁴

The Wisconsin-proposed waivers from SSA offer important new ideas about potential strategies to increase income preservation and asset growth for individuals with disabilities who return to work. Evaluation of these approaches to advance self-sufficiency and evidence of favorable outcomes will offer important new ways to encourage federal adoption and national replication.

3.4. Maryland State Innovation

Maryland's Statewide Special Transportation Assistance Program (SSTAP) is an example of an effective approach to the transit and paratransit needs of individuals with

disabilities. In many areas across Maryland, jobs and job seekers are far apart, often across county and city lines. This gap is even wider for people with low income. In addition, many companies across the state face a shortage of workers, especially entry-level employees.³⁶⁵

With this in mind, the Maryland Mass Transit Administration (MTA), in conjunction with Governor Paris Glendenning's Coordinating Committee for Human Services Transportation, worked with local jurisdictions to develop Maryland's Job Access and Reverse Commute Program. This program has allowed the state to develop transportation services to meet local community needs and link workers with job opportunities. A map describing projects funded through the state's Job Access and Reverse Commute Program is available.³⁶⁶

Through the SSTAP, Maryland has taken steps to greatly improve paratransit service for residents with disabilities, while exploring methods to reduce reliance on paratransit by enabling greater access to fixed-route transit. Maryland's approach to transportation for individuals with disabilities increases their independence and access to means of asset development, including education and employment.

3.5. Kentucky State Innovation

Kentucky has taken a "carrot and stick" approach to its housing policy through its Universal Design Program. In order to receive funding or subsidies from the Kentucky Housing Corporation (KHC), builders are required to follow guidelines designed to ensure accessibility and ease of movement for individuals with mobility challenges.

KHC's universal design policies have wide support from the legislature, and from the people they are designed to serve. People with disabilities have a wide range of housing needs and preferences. In recent years, people with disabilities and their advocates, supported by the U.S. Supreme Court's 1999 *Olmstead v. L.C.* decision, have focused on the right of people with disabilities to live as independently as possible. This has led to increased targeting of tenant-based vouchers (both federal vouchers

and vouchers secured by the HOME Program) for people with disabilities. States can better serve the housing needs of their citizens by leveraging funding and tax credits as incentives to build accessible housing, following Kentucky's model of universal design.

At a federal level, lessons learned from Kentucky's pairing of financial incentives with universal design requirements for single and multifamily development could be adopted for nationwide replication. HUD, which funnels housing financing to the states, and the U.S. Treasury, which distributes low-income housing tax credits to the states, could require the adoption of universal design standards.

3.6. Washington State Innovation

Washington is the first state in the nation to specifically address the needs of individuals with disabilities in its Individual Development Accounts legislation. The State of Washington matches savings that are deposited into IDAs by individuals with low income. The state includes a provision for people with disabilities by allowing the funds to be used for assistive technology.

By allowing IDA funds to be used for assistive technology, the state supports the asset development of individuals with disabilities, enabling them to earn and save income. It is necessary that IDA dollars not become a penalty against Medicaid and SSI eligibility in order for the program to be widely utilized by people with disabilities. The Washington State Legislature recently approved amendments to the state IDA Program. These amendments increase funding and expand the assets for which an individual can save, to include assistive technology and automobiles. The Washington Department of Vocational Rehabilitation will be requesting a waiver from Social Security so that non-Assets for Independence Act IDAs will not be considered as resources, nor will they affect benefits for individuals on Supplemental Security Income.³⁶⁷

More research needs to be conducted on the success of state IDA programs in fostering financial stability and independence for people with disabilities. States can replicate

Washington's program by explicitly including people with disabilities among other groups that are disproportionately affected by poverty in their IDA programs.

At a federal level, a compelling case can be made to amend the Assets for Independence Act to allow for the additional asset-building goals of purchasing technology, funding transportation, or paying for home improvements. These goals would enhance the level of participation of people with disabilities.

3.7. Conclusions

The innovative state strategies of direct and indirect financial incentives presented in this chapter offer diverse opportunities to establish or amend existing federal policies based on current experience. It is clear that no single solution effectively addresses all life domains for individuals with disabilities. It is imperative to find ways to combine these innovative state policies and programs to allow for greater financial security, improved access to housing and education, better health care, and sufficient transportation to promote community participation.

Each state above has embraced principles of self-determination with varying degrees of choice and control. This has led to expanded opportunity for greater numbers of people to manage and direct public and private resources. These six states were selected because they have an ongoing, intensive, comprehensive planning process that involves a full range of stakeholders—from state officials to providers to advocates and people with disabilities themselves—and the commitment and support of the governor and legislature.

Each state has recognized the importance of financial incentives to change thinking and motivate a change in behavior by multiple stakeholders. For the individual and family, direct financial incentives are offered to stimulate saving for lifelong housing needs and asset development that will advance economic status and community participation. For developers and a range of service providers, financial incentives are offered that will change the design of housing and transportation systems. These financial incentives

will indirectly benefit individuals with disabilities and their families and also enhance opportunity for social, civic, and economic engagement in more livable communities.

An equally compelling finding from the analysis of the six state examples is the variety of approaches to funding the financial incentive. In a majority of the examples, there is recognition of the merits of cost sharing to accomplish the identified social objective. In each of the examples, the state will allocate public resources contingent on leveraging individual or other private resources. Whether the vehicle is an individual account for education or is the buy-in to continued access to Medicaid benefits, there is a clear intent of shared responsibility in the interest of the individual, family, and public.

The Missouri example is yet another alternative approach in the public interest that spreads the cost of communication access across all users of telecommunications services to benefit individuals with disabilities who have additional needs. Finally, Kentucky, using a “carrot and stick” approach, succeeds in advancing public policy to expand availability of accessible housing by tying the requirements to public financing for development.

As key stakeholders examine NCD’s proposed conceptual framework for the 21st century of direct, indirect, and community-based financial incentives to advance the social and economic freedom of Americans with disabilities, the state lessons in innovative policy and program development will offer important choices for adoption to stimulate national replication.

Chapter 4: A New Financial Incentive Framework for Individuals with Disabilities: A Review of the Proposed Framework, Application to Case Studies, and Cost-Benefit Analysis

4.1. Introduction to a Conceptual Framework

In 2004, the President's Committee for People with Intellectual Disabilities explained the following in its *Report to the President*:

Historically, public assistance in exchange for enforced poverty and the absence of freedom is a bad deal—one that fails all parties to the arrangement; people with intellectual disabilities, their families and the American people. A great challenge before the United States government and society is to will a public safety net that permits people with intellectual disabilities to pursue economic and personal freedom and leads them to achieve the goal in a systematic way.³⁶⁸

The research conducted for this study on financial incentives reviewed and analyzed public policy across all the major life domains: education, employment, transportation, health care and long-term services and supports, income maintenance and asset development, and housing. In each area, the research team focused on barriers and facilitators to the advancement of greater economic independence and a better economic future for individuals with disabilities and their families. The analysis produced seven overarching findings that provide a platform to develop a 21st century conceptual framework in keeping with the core principles of ADA to promote full community participation, independent living, and economic advancement.

Seven Key Findings Pertaining to the Proposed Conceptual Framework

1. Financial incentives in tax and social policy are complex, poorly communicated, and underutilized.

2. Means-tested eligibility for public benefits entitlements (Social Security, Medicaid) deny many individuals with disabilities the opportunity to preserve income, save, and build assets.
3. Financial incentives in tax policy that promote asset building are out of reach to low-income wage earners who do not itemize.
4. Financial incentives across the major life domains (e.g., education, housing, employment, and health care) impact people with and without disabilities directly and indirectly through third-party community-based entities and employers.
5. Americans with disabilities will benefit from existing and new financial incentives strategies only through targeted and customized outreach that communicates information, training, and technical assistance in formats that are accessible, understandable, and relevant for all ranges of ability.
6. There is no single financial incentive that either directly or indirectly can produce a better economic future for individuals with disabilities. Many incentives overlap in their goals and together offer a combined and cumulative response to the challenges of poverty for Americans with and without disabilities.
7. Some financial incentives incorporate a universal approach and offer benefit to a large class of individuals with and without disabilities. Some financial incentives require modification to provide parity for people with disabilities compared to their peers without disabilities.

4.2. Principles for a 21st Century Conceptual Framework: Policies Optimizing Workers' Economic Reach (POWER)

NCD has a strong record of accomplishment in the development of policy recommendations that have been enacted into law and regulation. From advocating for the passage of ADA to being a leading voice for change related to emergency planning

and response, NCD consistently has raised expectations for individuals with disabilities and their families about public responsibility to advance the benefits for all within livable communities. There is no other single disability policy that quite captures the inadequacies of existing civil and human rights for Americans with disabilities as does the topic of asset development. For many Americans, tax and social policy supports building assets in multiple ways. For many Americans with disabilities, tax and social policy not only fails to support asset-building objectives, it actually prohibits such activities and outcomes.

To create a conceptual framework that sets a clear direction and supports increasing economic status for people with disabilities, NCD first lays out a set of overarching principles and then proposes core strategies. The conceptual framework has been identified as Policies Optimizing Workers' Economic Reach (POWER). There is no single financial incentive that will make the difference. In fact, it is a combination of strategies that both modify existing policies and enhance indirect community-based and employer incentives that can provide a comprehensive blueprint for change.

Financial Incentives Principles

- A. Financial incentives form a tool for public policy to advance the ADA goals of equality of opportunity, independent living, and economic self-sufficiency.
- B. Individuals with disabilities, regardless of age, economic status, or type of disability, and their families should have a range of choices to benefit from financial incentives across life domains.
- C. Direct and indirect financial incentives overlap in terms of opportunity to benefit from fuller community participation.
- D. Disability-specific financial incentives must be complemented by financial incentives with more universal impact than allowed by existing policy in order to

encourage access and use by people with and without disabilities in livable communities across life domains.

Financial Incentives Core Strategies

This section describes each of the POWER strategies, identifies the elements suggested for implementation, and explains challenges that people with disabilities face in navigating the major life domains. The section also details how implementation of the proposed POWER provisions would alter existing public policy. POWER strategies A through D and their corresponding elements are as follows.

POWER STRATEGY A: Modification to Entitlement Policy – Encourage work, income preservation, and asset building through changes to entitlement policy.

Four elements are suggested for implementation, as follows:

- A1) Raise resource limits for SSI to \$20,000 and index it annually for inflation thereafter with no loss of benefits for five years of working at or above substantial gainful activity (SGA).
- A2) Enact an earnings offset for SSDI beneficiaries that parallels the work incentives for SSI.
- A3) Modify income and resource limits through simplified Medicaid Buy-In that allows work and access to health care for five years regardless of income level.
- A4) Expand Plan for Achieving Self-Support (PASS) to allow for savings for home ownership or any asset-building goal including the purchase of assets that will generate income in later years.

The work disincentives inherent in SSDI and SSI are well known and need limited discussion here. Barriers are identified in NCD's Social Security report titled *The Social*

Security Administration's Efforts to Promote Employment for People with Disabilities: New Solutions for Old Problems (<http://www.ncd.gov/newsroom/publications/2005/ssa-promoteemployment.htm>). Any new model, if it seeks to promote employment, must address the barriers in new and innovative ways.

SSDI, and SSI to a lesser extent, express a bifurcated notion of employment as an all-or-nothing concept. An individual is deemed either able or unable to work—a situation that has resulted in provisions that lead to precipitous declines or total loss of cash benefits as income is earned. The widely recognized problem is that these declines occur with a speed and at a slope that result in benefits being lost before income is sufficient to replace them, and certainly before income streams from employment are stabilized and reasonably assured of continuity.

The POWER conceptual framework proposes provisions that lengthen the period over which cash benefits decline, reduce the steepness of the slope of benefit loss, and more realistically reflect the experience of people seeking to enter or to return to work. Two alternative approaches are offered for consideration. The first is no loss of cash benefits for a five-year period and the second is a gradual reduction of cash benefits.

A1) Raise resource limits for SSI to \$20,000 and index it annually for inflation thereafter with no loss of benefits for five years of working at or above SGA.

Raising the resource limits for SSI would encourage individuals with disabilities to save and build assets. Funds set aside in individual accounts toward a specific asset-building goal such as purchase of a home, transportation, or a business start-up would be exempt from any resource limit.

A2) Enact an earnings offset for SSDI beneficiaries that parallels the work incentives for SSI.

The alternative approach would involve not time but income. Under this approach, benefits would fall by a specified amount as income rises, so that, for example, once

earnings from employment equaled pre-employment benefits, benefit levels would fall by 20 percent. When earnings from employment reached double the original benefit level, the cash payments might decrease by an additional 20 percent, and so on. This could occur over a short or long period of time, depending on the upward mobility and career structure of the employment. In any event, the earnings should be secure to some reasonable degree. A one-time consulting contract or a temporary job after years of unemployment or a probationary position should not be enough to trigger the reduction.

A3) Modify income and resource limits through simplified Medicaid Buy-In that allows work and access to health care for five years regardless of income level.

Health insurance benefits are in some respects a bigger issue in the disincentives context than are cash benefits. Potentially, their economic value dwarfs that of cash payments. Although there have been several attempts to attenuate the risk of benefit loss under the Medicare or Medicaid programs, the net result appears to be impenetrable complexity. Here again, a simple and clear experimental solution is required and proposed in the POWER conceptual framework.

Health insurance should be maintained without any complexity or other source of worry for at least the first five years of employment, or until comparable private sector coverage is obtained. In the event such coverage is not forthcoming, the existing coverage should be continued indefinitely. Different administrative approaches will exist under the Medicare and Medicaid programs for bringing this about. Under Medicaid, which would be the primary coverage at issue for SSI recipients, expansion and federal responsibility for the Medicaid Buy-In Program would appear to be the optimal solution. Such a solution provides a consistent benefit option regardless of where a person lives and works and reduces costs to states that have been reluctant to expand the Medicaid Buy-In option for fear of their expanded responsibility to cover their share of costs.

A4) Expand PASS to allow for savings for home ownership or any asset-building goal including the purchase of assets that will generate income in later years.

The fourth element of POWER Strategy A allows for expanded utility of the PASS work incentives provisions to encourage long-term income preservation and asset building. The purchase of a home and the creation of equity over time is an important asset-building strategy that is out of reach of most current SSI beneficiaries. The greater flexibility of purpose to establish a PASS with the complementary lifting of the low ceiling for resources, with the individual still eligible for SSI benefits, offers a clearer path to a better economic future.

POWER STRATEGY B: Modification to Tax Policy – Modify tax policy to encourage work, income preservation, access to health care, transportation, continuing education, home ownership, and other asset-building goals.

- B1) Bundle and revise Business Tax Credits for more efficiency and use (Disabled Access Credit, Architectural/Transportation Tax Deduction [barrier removal], and Work Opportunity Tax Credit).
- B2) Revise the Impairment-Related Work Expenses (IRWE) exemption so that it applies to any reasonable expense incurred for the purpose of employment.
- B3) Revise Medical Expense Deduction threshold requirements and waive the need for deductibility.
- B4) Amend 529 Plans created exclusively for families with children going on to higher education to include purposes and goals other than saving for higher education that meet the needs of families that have children with disabilities.

Three major provisions of the Internal Revenue Code are designed to stimulate the hiring of people with disabilities. GAO studies referenced throughout this report have found them ineffective, underutilized, and widely unknown. Indeed, this finding suggests

there is reason to doubt that any tax-based incentives could materially improve the employment picture for Americans with disabilities. Moreover, there are people who question whether tax provisions aimed at achieving this goal may not have the paradoxical effect of reinforcing antiquated notions of disability and preserving undesirable attitudes and stereotypes. Pending development of a wholly new tax model—which is beyond the scope of this research—it is nevertheless useful to suggest incremental measures by which the impact of the existing tax provisions could be enhanced.

B1) Bundle and revise Business Tax Credits for more efficiency and use (Disabled Access Credit, Architectural/Transportation Tax Deduction [Barrier Removal], and Work Opportunity Tax Credit).

DISABLED ACCESS CREDIT: The Disabled Access Credit is a provision designed mainly to encourage small businesses to provide public accommodations to customers or clients with disabilities. It can be used for assistive technology, specialized employment-related services such as readers or interpreters, and other accommodations and auxiliary services as well. Its use in this latter regard has been hindered by several IRS interpretations of the law that drastically limit its scope in ways never contemplated by the drafters, according to the legislative history. One challenge is that ADA applies only to employers with 15 or more employees, and as a result, the IRS has determined that the credit should not be available to smaller employers since their accommodations cannot be mandated by the law. This interpretation contradicts the fact that the maximum size of an eligible business is 30 full-time employees or under \$1 million per year in gross receipts. Nothing in the legislative history suggests Congress intended to place a lower limit on the number of employees. Additionally, the definitions of eligible expenditures need to be clarified to make clear that the purpose of the expenditure, rather than the a priori nature of the item or service, will be determinative. Finally, the current limitation in the amount of the credit to 50 percent of the first \$10,000 in eligible expenditures should be eliminated.

ARCHITECTURAL/TRANSPORTATION TAX DEDUCTION (BARRIER REMOVAL):

This is an arcane provision that needs to be revised substantially. It allows specified capital expenses to be converted into deductible ones, meaning that instead of being amortized or depreciated over a number of years, they are accelerated by being taken in the year incurred. The definition of qualifying expenses is narrow and outdated, however. If the provision is to have any meaning, the scope and definition of eligible expenses must be broadened, the provision must be melded with the Disabled Access Credit, and the guidelines used to determine whether claimed expenses qualify for the deduction must be updated. Ideally, the provision should be eliminated, merged into an expanded access credit, and available to all businesses, with gradual phase-out based on business size or profit levels.

WORK OPPORTUNITY TAX CREDIT: This tax credit provides hiring incentives for a number of hard-to-employ groups. Two groups, predominantly oriented toward disability, are included: SSI recipients and people referred by state VR agencies. This is an arbitrary and narrow slice of the job-seeking population with disabilities. Albeit perhaps in totally different capacities, people seeking to return to work with their former employers, should again benefit the employer with use of the credit. The credit currently targets only first-year wages, thus giving no incentive for retention or advancement in employment. The proposed change would allow a continuing benefit to the employer for up to three years.

Individual income tax provisions also play a role. Two are particularly worth noting: the IRWE and the Medical Expense Deduction.

B2) Revise the IRWE exemption so that it applies to any reasonable expense incurred for the purpose of employment.

IRWE is an underutilized tax deduction that allows individuals to claim an itemized deduction for certain costs incurred “in connection with the place of employment.” Interpretations of this provision are few, but it was intended to pay the costs of attendant services at the place of employment. IRWE has been used more broadly, and needs to

be clarified to explain that it applies to any reasonable expense incurred for the purpose of employment. The expense could and should include the pro rata costs of home-based personal assistance services on days when an individual uses such assistance to prepare for and go to work. Modifications to IRWE also should include the add-on costs of transportation attributable to the disability. Whatever costs IRWE does or does not include, it will continue to be of little value to most people with disabilities as an itemized deduction without modifications. Fewer than 40 percent of taxpayers itemize, and such expenses are likely to be incurred disproportionately at the outset of employment, when income against which to offset the deduction is at its lowest. Accordingly, an above-the-line deduction, not subject to the ability to itemize, should be substituted. This adjustment or credit should be subject to carryover, meaning that it can be carried forward or backward for a specified number of years, so as to provide maximum leverage to the taxpayer.

B3) Revise Medical Expense Deduction threshold requirements and waive the need for deductibility.

Many disability-related costs, including costs of equipment and services used in employment, qualify for the Medical Expense Deduction. Much assistive technology (however and wherever used), service animals, and other costs fall into this category. The tax case law is replete with examples of items granted deductibility by reason of their purpose or their features, reflecting an intention to overcome or mitigate the consequences of a physical disability. However, this case law is little known or understood, even by many tax professionals. One reason may be that the Medical Expense Deduction is hard to claim. Once again, itemization is required, but in addition, one's allowable medical expenses must exceed 7.5 percent of adjusted gross income (AGI) before they are deductible. This means that a certain proportion of such costs likely will be lost, unless one has enough medical expenses from other sources to meet the AGI threshold before taking assistive technology (AT) or other disability-related costs into account. Accordingly, at least so far as disability-related costs involved in achieving a level playing field are concerned, the requirements for a threshold and the need for deductibility should be waived. Need is not apparent for broadening the scope

or definition of what is deductible, although much need for professional and public education on these points remains. From the legal standpoint, all that is required is that the conditions for obtaining the tax benefit be modified. Because timing also is a factor here, the new above-the-line deduction or credit should benefit from the flexibility that carryover would afford.

B4) Amend 529 Plans created exclusively for families with children going on to higher education to include purposes and goals other than saving for higher education that meet the needs of families that have children with disabilities.

There are a number of additional ways the tax law could advance economic independence with and for employment of people with disabilities. The personal development accounts paralleling accounts for education under Section 529 of the Internal Revenue Code present one example. The proposed POWER framework would allow families with children to save for purposes other than postsecondary education to create a better economic future. Examples of what would be allowed include start-up of microenterprise; purchases for assistive technology or transportation; and savings for nondegree education and training. This amendment would advance the full participation in society and self-sufficiency of young people with disabilities transitioning into adulthood by allowing them and their families to save and plan for the future.

POWER STRATEGY C: Enhance Direct Asset Building – Encourage savings and asset building through direct opportunities. Utilize individual budgets, matched savings plans, financial education, and cross-agency collaboration to leverage resources and advance social and economic status.

C1) Expand and refine Individual Development Accounts to meet the needs of people with disabilities.

This can be accomplished through several steps. Include transportation and technology as a purpose for saving. Provide incentives to encourage a private match to federal funds. Allow private and state-authorized and -funded IDAs to adopt federal IDA rules

that exclude counting the resources for purposes of continued eligibility for public benefits. Require financial education to be conducted in accessible locations with accessible content and be accessible online.

C2) Encourage financial education as part of an individual's education and work plans.

This would include IEPs, Transition Plans, Plans for Employment through VR, and the Workforce System.

C3) Issue an Executive order to federal agencies for cross-agency collaboration and coordination.

The order would identify responsible parties and timeframes. First, create a time-limited task force that includes these agencies and departments: Education (Office of Special Education and Rehabilitative Services/RSA), Labor, SSA, Treasury, HHS, Centers for Medicare and Medicaid Services, IRS, Transportation, Office of Management and Budget, VA, Commerce, HUD, and Small Business Administration. Set a time limit of six months to identify policy and practices barriers and propose interagency solutions and cross-program and funding authorities. In addition, create a task force chaired by the Department of the Treasury and the Office on Disability at HHS to lead the interagency collaboration.

C4) Simplify implementation of individual budgets.

Key components are cross-agency work. Invite SSA, the Department of Education and its Rehabilitation Services Administration, departments of Education, Labor, Health and Human Services CMS, and Substance Abuse and Mental Health Services Administration (SAMHSA) to collaborate in developing a cross-agency template that simplifies the implementation of unified individual budgets that promote self-determination and person-centered plans for adult living. The strategy would allow savings and asset-building rewards that permit an individual to keep 50 percent of what

he or she does not spend in an individual budget. The savings must relate to a specific asset-building objective in an individualized plan.

POWER STRATEGY D: Enhance Indirect, Community-Based, and Employer

Incentives – Provide incentives to employers and communities to offer individuals with disabilities indirect benefits that promote affordable and accessible housing, asset-building strategies, and a road map out of poverty.

D1) Consider revision of housing design standards.

In two requirements, HUD would (a) adopt universal design standards developed by the Access Board; and (b) require that the adoption of universal design standards become a condition for any entity that receives HUD financing for single or multifamily dwellings.

D2) Require a qualified allocation plan set-aside for 20 percent of units.

All units receiving Low-Income Housing Tax Credits (LIHTCs) should adopt new universal design standards and reserve 20 percent of units to be affordable to individuals with disabilities who are at or below 30 percent of average median income (AMI).

D3) Establish a New Markets Tax Credit.

Require each federally funded project that is creating jobs to document job creation, outreach and recruitment efforts, and the number of people with disabilities hired.

D4) Provide employer transportation and housing deductions.

Employers receive a tax deduction for the costs of assisting employees with disabilities with transportation and first-time home ownership.

D5) Demonstrate a tax aid program for Americans with disabilities.

The federal government would provide free tax assistance and filing services to millions of Americans with disabilities. Use this process as a gateway for other asset-building opportunities. In addition, build financial and tax education and financial services infrastructure.

D6) Establish employer-matched education accounts.

Allow employees who contribute up to \$500 to an education and training account to receive a tax credit for their contribution. Allow an equal match from their employer that would be deducted from corporate income taxes. Individuals must earn less than \$25,000 to be eligible for the benefit.

4.3. Application of the POWER Framework to Case Studies

The next step in the research design was its application to four individual situations.

Three of the four case study profiles (numbers 1, 2, and 4) represent the real experiences of people with disabilities. Case study 3 is based on a composite picture of experiences that represent a significant number of families raising a child with developmental disabilities. In each case study, the current experience of the individual and/or family is described and then contrasted with the experience that might be possible if POWER were applied.

Case Study 1: Mary: SSI Recipient Attempting to Enter the Workforce

Mary is 30 years old. She has a disability and has never held a job. She is receiving SSI (\$603 a month), which is the federal benefit rate for calendar year 2006. In Mary's state (Indiana) there is a state supplement of \$85 that she is receiving, bringing her monthly cash benefit to \$688. Mary has no other income and receives no other cash benefits, but she does receive Medicaid and other in-kind benefits that will be discussed later. In her state, receipt of SSI benefits automatically confers entitlement to Medicaid.

Mary has been offered a 25-hour-a-week job. She wants to accept the position, but she is worried. Apart from all the concerns that accompany embarking on a new career, Mary, as a person with a disability, confronts an additional and very distinct concern. If she takes the 25-hour-a-week job, paying \$5.15 an hour, her benefits will be jeopardized. She understands that as an SSI recipient she will be subject to benefits reductions because of any other income, earned or otherwise.

Broadly speaking, Mary understands that her cash benefits will be reduced by roughly \$1 for every \$2 she earns over the first \$85 of income per month. She further understands that should her benefits be reduced to zero, her Medicaid (her only source of health care) could be jeopardized as well.

But Mary also understands that there are various provisions in the law, called work incentives, that could reduce or prevent these adverse consequences of employment. Before she can find out about them, she does an initial computation of what her benefits would be if she simply starts work.

PRE-INCENTIVES COMPUTATION: Mary's first problem is that she will be paid weekly, and she knows that SSI computes income, resources, and benefits on a monthly basis. Not knowing that the standard calculation is 4.3 weeks per month (and even that can be disrupted by actual payroll dates for weekly or biweekly employees), she decides to divide her annual wage by 12. Figuring \$5.15 an hour, 25 hours a week, times 52 weeks (she assumes she is paid for holiday, vacation, and sick days) she comes up with a salary of \$128.75 per week, or \$6,695 per year, which when divided according to her common-sense formula is estimated at \$557.91 per month. Mary suspects it is permissible or even necessary to round off, so she does, to \$558. Of course, had it occurred to Mary to round off her weekly income to \$129, then her monthly income would be \$559 (based on 52 weeks times \$129, which equals \$6,708, divided by 12).

Mary wonders if it is not a little absurd to try to grind the gears of income and expenses this finely. Well, Social Security does, so she guesses she must as well.

BENEFITS REDUCTIONS: Mary now calculates her benefits loss—first without reference to the even more mysterious work incentives. She first adds her \$558 wages plus her \$688 SSI payment. That would be great; it would be \$1,246. But she then begins the further computation as she understands it, including how much of her first \$85 of income will be “disregarded,” meaning that it will not be included in “countability,” which is SSA’s term for income. Countable income is to the SSA recipient what taxable income is to the taxpayer.

Mary’s remaining income from her wages after the \$85 disregard is \$473 per month. She knows she will lose half of that, or \$236.50. She subtracts \$236.50 from her \$688 SSI payment and is left with \$451.50. She knows she can round off, but she is not sure whether to round up the \$451.50 or the \$236.50. She decides to round up her benefit, so is left with an SSI benefit of \$452. Adding this \$452 to her wage of \$558, she comes up with monthly gross revenue of \$1,010 from all sources.

NET GAIN: So how much better off is Mary’s bottom line? She started with \$688 a month and now, after working 25 hours a week (an average of 108 and a third hours per month [call it 108]) ends up with \$1,010. This is a gain of \$322 a month. For 108 hours of work, it comes out to \$3 an hour. Before taxes, work expenses, clothing, and transportation on the downside, and these work incentives on the upside, this is less than the federal minimum wage.

INSURANCE: Mary learns that her future employer provides contributory health insurance to her coworkers. She is told, however, that she would not be eligible until expiration of a six-month waiting period. In any event, inquiry of the personnel and benefits office reveals that the particular health services she needs to keep her disability under control either are not covered or, if covered, are subject to a low dollar limit (or cap). “At least,” Mary sighs gratefully to herself, “I have Medicaid. While far from ideal, it allows me to get the basics of specialty services that I need.”

Mary understands that if her cash benefits were to cease, her Medicaid might be thrown into jeopardy. As a minimum-wage worker, she has little immediate prospect of seeing

her SSI cash benefits zeroed out, but she does look forward to steady pay increases and promotions through her hard work and eagerness to learn.

Mary calculates that if her salary were to reach \$1,461 a month (at 25 hours a week, about \$13.50 an hour, but less per hour if her hours are increased), her benefits would be reduced to zero. That \$1,461 would represent twice her full SSI payment plus \$85. At the \$1 for \$2 reduction rate, a countable income of \$1,376 would eliminate \$688 in SSI—her whole payment. Meanwhile, at least pending these work incentives, she knows that for every dollar her salary goes up, she effectively will bring home 50 cents more.

OTHER INTERIM CALCULATIONS: Whatever her gross salary, Mary is of course not taking home an average of \$558 a month in wages or anything close to it. Her gross pay is reduced by 7.65 percent for her Social Security and Medicare tax (\$42.69 a month), by one-dependent federal and state withholding exemption (\$55.80 a month), and by other mandatory exactions (workers compensation and short-term disability—totaling \$5.58 a month). These deductions total \$104, leaving her net wage, before work incentives, at \$454.

RESOURCES: Mary would like to save for education. She knows that grants, VR support, and other third-party sources may be available, but she also knows that they would not cover the entire cost of college, especially when needed AT and personal assistant services (PAS) are added to the mix. She is willing to work for \$3 an hour (even \$2.02 an hour after taxes) if she can save the money toward an education. She knows that it will take a while, but realizing that SSI limits her countable resources to \$2,000, Mary wonders if there is any point. Fortunately, as a determined person, she decides she will find out about and use the work incentives if she can.

If Mary lived in one of the 11 so-called Section 209b states, where Medicaid does not come along automatically with SSI eligibility, then even more complexity would arise. The next case study will involve a person residing in one of those 11 states. Since Mary

is in no immediate jeopardy of losing all her benefits, her Medicaid is safe. Therefore, the scenario will not depict her looking into how to protect this vital noncash benefit.

Mary's immediate problem can be understood on two levels. First, she needs to find someone who can help her understand the work incentives. She has looked at the Social Security Administration's Web site, finding both the Code of Federal Regulations and the Program Operations Manual System. These are the sources of the governing rules, she knows, but to her, an ordinarily intelligent high school graduate, they are written in incomprehensible legalese, even in the supposedly simplified examples, and they use terminology, cross-references, and qualifiers that are totally unfamiliar to her. At length she concludes sadly that she would have about as much luck figuring out what to do with these sources as she would by checking a medical textbook in order to perform do-it-yourself surgery.

Mary figures that perhaps her cousin, an accountant, can help her. After all, doesn't she help people with their taxes? However, her cousin works only for people who can pay her, and even for a family member she cannot help Mary because she does not know anything about the subject. She suggests that maybe the local Certified Public Accountant association has a pro bono division. Another cousin who is a lawyer also has no relevant knowledge.

But Mary's VR counselor has heard that various benefits counseling resources exist in the community. The VR counselor has some acquaintance with the subject but is not permitted to give official advice beyond the scope of the VR Program. Leaving aside all the twists and turns, Mary eventually comes into communication with the WIPA Program (formerly Benefits Planning Assistance and Outreach).

WORK INCENTIVES: Mary, at length, makes her way to a knowledgeable and patient benefits counselor who could help her. She tells Mary of two key provisions that might help. The first is IRWE, which can reduce Mary's countable income by the amount of expenses that she incurs in order to work. In Mary's case there are two immediate expenses: her \$104 in taxes and the \$5 per day she spends for parking her modified

vehicle. Because she works five days a week, with an estimated 20 days missed a year for vacation and holidays on which she does not travel to work, the taxes (\$1,248) plus the parking total \$2,448 a year, or \$204 a month. Subtracting this from her countable income brings the number down to \$269 (\$473 minus \$204). At \$269, her SSI benefits reduction is only \$134.50, making her SSI payment \$553.50 or \$554. That \$554 plus her \$558 monthly income yields a gross cash flow of \$1,112. With the \$104 in taxes subtracted from her monthly income, as well as her benefits reduction, Mary's net cash flow is reduced to \$1,008 per month. She thus is no worse off for having paid the taxes, because SSI has made up the difference, but she is no better off either. This is how it will be with all IRWE.

These are the expenses that Mary knows she will incur when she starts work. Her benefits counselor needs to do further research on whether any allocation for mileage, lunches, or other costs also might be excludable from countability. Other expenses from which Mary would benefit include some incidental AT devices and training in the use of such devices. The counselor subsequently will factor in these expenses, but Mary's biggest problem is the dawning realization that even if she can save more money as a result of the work incentives, it still may not be worth the trouble, since her savings (or resources) are limited to \$2,000.

That is why Mary is so excited to hear about the other work incentive—PASS. Mary's counselor explains that by setting aside designated funds in a separate account for specified self-support activities and goals to be achieved over a "reasonable" period of time, Mary can exclude more of her income and, more important, potentially can save far more than \$2,000, which under PASS would be excluded from resource countability. The costs of maintaining the account also will be excludable from income, but Mary does not know the status of any interest that she might earn.

Mary also learns that PASS is subject to approval by the SSA. She understands that a regional work incentives team (or cadre) will review her application, and that a lengthy, complex form, the SSA 545, must be used to make the application. Upon obtaining the form, she finds there are a number of troubling aspects.

For one thing, she does not have a specific vocational objective at this early point. She knows that higher education correlates with income, and that a college degree generally grants access to a wide range of jobs and to various sorts of upward mobility. However, SSA seems to expect Mary to specify a vocational objective. It is against this specified objective that the viability of all her proposed savings, expenditures, and time frames will be assessed. Against some standard of feasibility or suitability, SSA experts also will adjudicate Mary's request by considering the factor of suitability for someone with her disability. Mary resents the notion that total strangers should have the right to sit in judgment of her and control her life this way, but she knows she has no choice.

There are some things that Mary does not know. Generally, she does not know if SSA takes into account the overall correlation between education and income in calculating whether approval of her plan is likely to save the government money over the course of her working life, an estimated 30 years. She certainly does not know how SSA decides what work people with her disability are capable of doing, or how SSA would factor in the possibilities resulting from an education that she has not yet received, with a major she has not yet picked, and an occupational goal she will now quite probably have to fabricate.

In addition, Mary knows that, independent of her school choices, changes in her income or work expenses could change the plan, or necessitate its change. With events that are known to her, Mary understands it will be possible to amend the plan, and she would do this if, for example, the four years and six months she postulated for school (a full four-year academic course plus six months to find a job) needs to be changed. This change could happen if she is required to take a reduced course load. But how long will she need to work before she is ready to quit her job and go to school full-time, or would it be better for her to try to work part-time while going to school part-time? These questions all have powerful economic aspects, but they involve so much more. Mary's benefits counselor does not feel qualified professionally to advise her on anything beyond the legal and benefits-related dimensions. Mary's VR counselor can tell her only the rules of the VR Program.

As Mary is considering her options, some unforeseen developments occur that complicate her decisionmaking even further. Mary lives in subsidized housing. She discovers that in a Section 811 project or a Section 202 subsidized project, she pays 30 percent of her “adjusted income” toward the costs of her rent. If her countable wages also are treated as part of countable income for HUD purposes (a different legal test than SSI uses), then her rent will go up and further reduce her net gain. With SSI countable income of \$454, her housing cost could rise by \$136 a month. This shrinks her net monthly cash flow to about \$870, or just \$192 more than she was getting with SSI alone.

What about the food stamps that Mary also has been using? Most jurisdictions would not curtail her food stamp allotment as long as her income remained below the federal poverty level, and the hope is that Mary’s is one of those jurisdictions. Otherwise, potentially a third of her average \$100 worth of food stamps per month could be at risk. If this were the case, her real net cash flow would go down by the \$33 a month necessary to replace this in-kind benefit.

Mary is fortunate in one regard. She does not need low-income home energy heating assistance. If she did, and if it were tightly tied to income, then an increase in her income, from whatever source, might lead to a decrease in that subsidy too. But Mary’s housing project pays for utilities.

Because of her total dependence on SSI and other programs for sustenance, Mary has qualified for lifeline telephone service, partially subsidized under the Federal Universal Service Fund. This gives her a guaranteed minimal amount of local phone service for about \$10 a month. She cannot determine whether her increased income and resources will disqualify her; her phone company’s special needs center leaves her on hold for an hour and its Web site does not say. But she calculates that if she were to be disqualified, her basic phone bill would go up to \$22 a month, or an increase of \$12. And with respect to housing, food stamps, utilities, and, potentially, phone, Mary knows only too well that increases in her income will result in increases in her pro rata costs, but on a slope that may be far too steep for her to climb.

Disdaining to calculate how much money she actually will have left, and motivated by the desire for economic autonomy above all else, Mary nevertheless determines to press forward. She realizes first of all that she will need to devote inordinate time to recordkeeping, accounting, time frames, and of course reporting to SSA. She has been told that SSA operates along several parallel tracks, meaning that sometimes reported earnings are not immediately or correctly credited to one's account, or that self-reported earnings are not properly credited. Because this could lead to erroneous allegations of income concealment, Mary needs to decide whether to take everything to her Social Security office in person (which costs time and money) and get a signed receipt, or to mail each item "return receipt requested" (which also costs money but takes less time). She does not think the costs of these precautions will be excludable from income. Mary realizes that even if she can prove she delivered documents, she cannot prove what was in them. She has heard many horror stories from friends and acquaintances, but has to trust that most of the time most systems work, even though the stakes are so high when they fail.

But Mary's problems are not yet fully revealed. She learns that the SSA regional work incentives team has the right to ask her questions about her PASS before approving it, and that the team has the power to reject or question her choice of vocational objective. What bothers her, now that she has decided to choose accounting as her career goal, is that the time frame for the cadre's decision is not entirely clear. Someone tells Mary it might be two weeks. Meanwhile, Mary's prospective employer, who will be claiming the Work Opportunity Tax Credit in connection with Mary's first \$6,000 of first-year wages, is anxious that she start working immediately. Mary knows that her PASS can be approved retroactively to her employment's start date, but what if it is rejected? Not only will she suffer the already-discussed drop in her monthly SSI, but she fears she will be hit with an overpayment assessment. She will not be charged with fraud since she did report her earnings, but an overpayment is an overpayment, fault or no fault. If she is charged with an overpayment (in the event her PASS is rejected utterly), she probably could appeal and get it set aside, but she has been told that under an obscure provision of the tax law she would be liable for taxes on the amount of any overpayment claim

that Social Security waives. It seems that “debt forgiveness” is includable in gross income for tax purposes.

Mary takes time to weigh the options, perhaps only a few hours too long—but too long it is. Her prospective, now erstwhile, employer reluctantly informs her that the offer has been retracted.

Disconsolate, Mary shows signs of discouragement and despair. Her excitement about employment potential fades. She stops talking to friends and family about her dreams and begins to withdraw from people in general. She finds herself unable to sleep through the night and begins sitting in front of the television countless hours each day. She feels sad each day and cries without knowing why. The complexity of the current rules and the limited support systems available to provide individualized advice to help her make informed decisions are not responsive to Mary’s needs.

Case Study 1: Application of the POWER Framework to Mary’s Situation

There are four parts of POWER that would encourage both work and savings for Mary. The most relevant is the raising of resource limits for continued SSI eligibility for a five-year period (see Element A1, p. 124). Mary would be allowed to retain her full SSI benefits (assuming she remains otherwise eligible, of course) and save any or all of her earnings toward self-support goals, which need not be specified in advance.

Under current law, the objectives for which a PASS can be approved, and hence the nature of permissible expenditures and the objectives of the expenditures, must be employment related. For people with limited education, limited skills, poor work experience, or limited stamina, the prospects of self-sufficiency through employment, while always worth pursuing, are statistically slim, even where the PASS mechanism can be brought to bear. Data regarding the proportion of people receiving approved PASS proposals and leaving the benefits rolls after one, five, or ten years are not yet available, but anecdotal evidence suggests that the number is only slightly larger than the overall number of SSI recipients who become independent through work. This is

particularly unfortunate since PASS users are likely among the most sophisticated and most determined of SSI recipients.

The decline in employer-sponsored fringe benefits, including health care and pensions, and the erosion of the entry-level job market contribute to the deterioration in upward mobility through employment for people with disabilities. Given this trend, policymakers need to understand that entry-level employment is unlikely to enable Mary to relinquish benefits. Policymakers may decide to reduce or strip her benefits, and may be indifferent to the hardship this will cause, but that is a very different way of solving the program cost-escalation problem. What policymakers must recognize, especially in an era when any thought of a property or contract right in employment has been abandoned, is that upward mobility must involve access to assets as well as access to employment. Allowing Mary to save from her earnings without restrictions sets the stage for both.

From the technical standpoint, there are several alternative ways the new disregard (raising the resource limit) could be implemented. Mary (and individuals in similar circumstances) need to have assurance of freedom from a monthly review that could result in a reversal of all her hopes and efforts. Additionally, she must have no incentive to conceal income, as some recipients, regrettably, have felt compelled to do.

If Mary were able to save all her \$6,708 a year for five years, she would emerge with a nest egg of \$33,540, not counting interest. At the end of five years, that money would remain untouched. If she needed to continue receiving cash benefits, the standard rules would apply to subsequent earnings and aggregations, but the \$33,540 would be hers, perhaps for education, perhaps for AT acquisition, job-related or otherwise, perhaps for the down payment on a home.

Under current law, Mary potentially could put all or most of her earnings in a PASS, but she could not use them to buy a capital asset such as a home or an annuity. If she worked, she could not use her earnings to fund an IRA or employer-sponsored contributory retirement plan.

When Mary was living under the old system, one of the things she heard whispers about was the Individual Development Account. She learned that IDAs represented a way to set aside earnings, as well as matching funds, for use in meeting a variety of personal objectives. Home ownership was included among the permissible objectives of the IDA, but the IDA aggregation upper limit of \$10,000 was too small to hold out much hope of propelling Mary into the asset-ownership sector. The IDA could be used to capitalize a business start-up, but not for employment. It could, however, be used for postsecondary education. So there was no coordination between PASS and IDAs.

If, as part of the POWER proposal, access to IDA and PASS plans could be unified and combined with the removal of artificial barriers between permissible usage, account administration requirements, time frames, and eligibility, the results could contribute significantly to the reconfiguration of social benefits as asset-development strategies in the ownership society. What is especially attractive about the IDA in this connection is the leverage it offers through the use of matching funds. With such funds available on a tax-favored basis, the nest egg could grow substantially.

And what are the odds that the amount that could be saved from Mary's wages for a self-actualizing, asset-development goal would be limited to the \$33,540? Freed from worries about keeping her income down, able to work more hours or accept raises, there is every reason to believe that Mary will be able to earn a great deal more.

Evidence for this likelihood can be found throughout the fabric of current economic and social policy assumptions. Incentive models, used increasingly to structure choices in a variety of settings, are predicated upon exactly these assumptions (see Element B2, p. 125). Tax policy, favoring the liberation of larger and larger amounts of income and capital, is predicated on the related assumptions that greater reward will spur greater effort and that such effort will redound to the benefit of the entire economy and society. These policies have by any measure produced excellent results for people who already own assets. Why should they not be deployed with similar benefits on behalf of people who yet aspire to that status?

Available data suggest that approximately 15 percent of SSI recipients are employed, yet fewer than 1 percent of beneficiaries leave the rolls for economic self-sufficiency reasons (www.SSA.gov).³⁶⁹ The existing system of work incentives does not work. Fewer than 1 percent of SSI recipients are utilizing PASS plans to preserve income and set aside resources for a work-related goal. POWER offers Mary a work incentive that is simpler to understand and that makes it easier to be a participant than does the existing system of limits, law, and reductions. Mary's unlimited earnings accumulation for five years enables her to set measurable and meaningful asset-building goals. The extra cost to the government is already there as Mary, without pursuing employment, simply continues to collect her monthly cash benefit. The baseline costs are already there.

By itself, a proposal such as this, if it allowed 1 percent of people who utilized it to get off the benefit rolls, would more than pay for itself over their average working lives. Meanwhile, during the five years, any potential excess in SSI expenditures would be partially offset by income and payroll taxes paid by and on behalf of Mary, by sales taxes paid by her on portions of her wages devoted to consumption, and by related benefits associated with retention of Medicaid.

For Mary to get the full benefit of her permissible savings, coordinated reforms will need to be implemented in related in-kind benefits programs. Most notably, for the duration of the five years, amounts Mary saved from employment or from matching-funds contributions to IRAs should not be taken into account in determining her adjusted income for housing subsidy purposes. In simplifying the administration of SSI and housing programs, it is likely that the changes recommended here will result in cost savings to several major public sector service systems as well.

Case Study 2: Melissa: Working-Age Adult Acquires Disability and Starts Her Own Business

At 42 years of age, Melissa led a quiet life in a good job. The existence of people with disabilities, and the issues facing them in day-to-day life, had rarely impinged upon her consciousness. If she thought about people with disabilities at all, it was with sympathy

bordering on pity when she watched a telethon and celebrities asked her to contribute funds to find a cure. All that changed one day. She heard the screeching of brakes, but the impact occurred before she even had time to turn to look. In the hospital and the rehabilitation facility in the weeks and months to come, Melissa went through despair, rage, denial, and then acceptance of her new status in the world.

At last, Melissa was declared medically ready and stabilized to return to her New York home. Her hospital and rehabilitation costs had been covered substantially by her employment-based insurance, but with her sick leave (which had provided income) exhausted, her health insurance having reached its cap, and the possibilities of returning to her former position as a construction worker considered infeasible, economic concerns rapidly joined emotional ones as Melissa faced her future.

Melissa's colleagues in the building trades rallied to support her and helped modify her apartment, including the public portions of the building needed for entrance and exit and the laundry facilities. The landlord initially had objected to modifications in the public spaces on the ground that they would make other tenants feel uncomfortable, but the landlord relented when promised that the original design would be restored, also at no cost, if Melissa moved.

Melissa found herself living on her savings, after her short-term disability benefits ceased and while the waiting period for SSDI ticked off on the clock. Learning about SSI and understanding that it typically included Medicaid coverage, Melissa thought of applying for this program, which would be available immediately if she met its eligibility criteria. Unfortunately, because she still had savings well in excess of \$2,000, she was told that she would not qualify for SSI unless she entered into a spend-down agreement or unless some other means could be found of exempting her savings, although shrinking, from "countability."

Various strategies for sheltering her resources were suggested to her, but none seemed appropriate. IDAs and IRWE were predicated upon the receipt of earnings, and Melissa had none. Use of the PASS might allow her to establish a savings process for future

self-support purposes, but then the money would no longer be available to meet her ongoing routine cash flow needs. Though she would receive monthly SSI payments once she qualified, these payments, without augmentation from her savings, would not be enough to meet her needs, including needs for goods and services that she regarded as indispensable to her care but that likely would not be covered under the state Medicaid Program or, as she learned from a knowledgeable benefits counselor at her local independent living center, under any of the state's existing Medicaid waivers.

Someone pointed out to Melissa that if she owned her home as opposed to renting it, then its value would be excluded from countability. She thought about using her savings as the down payment on a home, but then, just as with the spend-down, she would have to use what was left to pay the mortgage and would in all too short a time find herself without resources for meeting future goals that, with the passage of time and the clearing of her mind, might emerge as viable options.

But finally, Melissa obtains SSDI, and with it a monthly payment of approximately \$1,200. In addition, withdrawal from her remaining savings at the rate of about 4 percent of their value per year, allows her to subsist at current modest levels. Her life is austere, but she has kept her home, her dignity, and a reasonable measure of autonomy. What will come next?

Goals and Obstacles

By degrees Melissa comes to realize that her economic and personal prospects are not good unless something changes dramatically. She would like to get a job and feels she can work, but what could she do? Contacting the state VR agency, she undergoes various eligibility determinations, skills tests, and other assessments, and at length is deemed eligible for services, but her state is operating under an order of selection. She qualifies for services by reason of meeting the "most significant" disabilities criteria, but none of the training and placement opportunities known to the agency seems to interest her or makes full use of her skills.

At length Melissa determines that self-employment represents her best option. Inventorying her skills, she realizes that a computer-based enterprise, utilizing her blueprint-drafting and other construction management skills, represents the best pathway to independence. Little does she know that the Social Security Administration may have other ideas.

Melissa knows that she will need capital to start and sustain her business until a client base can be developed. But her problem remains how to get the initial funding necessary to purchase computers and other home-based equipment she will need and begin marketing activities. Three potential sources of this seed money come to her attention: her state VR agency, an equipment loan through the state program operated under the Assistive Technology Act, and a small-business loan guaranteed by the Small Business Administration.

Melissa learns that it makes a huge difference how she obtains these funds. If she obtains cash grants or loans, even if they are to be converted quickly into purchases, they are subject to treatment as income. While income per se will not jeopardize her SSDI payments, provided the income is unearned, Melissa is given to understand that her intended use of these funds could constitute an assertion by her that she is able to work. That in turn could jeopardize her monthly benefit, which is an all-or-nothing payment, depending on her eligibility status.

Though Melissa is not in immediate jeopardy of losing her monthly benefit, let alone her irreplaceable Medicare health coverage that comes with SSDI, she now understands that she may face real risks if she begins to earn income that exceeds a certain limit. Unless she can shield her income from countability, she will risk being deemed financially ineligible for benefits if her income exceeds SGA in at least nine months during a rolling 60-month period, thus deeming her capable of working.

Arranging to obtain her loans through direct third-party purchase of the work-related equipment she needs, rather than as cash, Melissa is able to begin her business. Her equipment has not given her all that she will need, since specialized drafting software,

enhanced fiber optic connections, and other expensive resources also will be necessary, but Melissa begins to earn a small income from her first few contracts. A friend tells Melissa that she will be entitled to nine months of trial work before the amount of her earnings can become an issue, and before SSA will consider the question of whether she is capable of engaging in SGA. But what Melissa does not understand is that the monthly income that constitutes SGA, an estimated \$900 as indexed for inflation this year, is not the same amount of income as will result in a month of trial work being charged to her record. The amount required for a month of trial work is far less.

Realizing the imprecision and complexity of rules and the precariousness of her situation, Melissa becomes all the more determined. As a result of hard and disciplined work, she is able to raise her earnings to the SGA level. But now she must be additionally concerned that her benefits will be jeopardized, and that income that exceeds the SGA level by as little as \$1 could jeopardize her entire benefit for the month, and potentially her eligibility for benefits in subsequent months.

What can Melissa do? She still does not have enough money for the equipment she needs to put her venture on a self-sustaining basis, but she risks losing the monthly cash payment she still needs long before she is capable of reliable self-support.

Melissa now begins to learn about Social Security work incentives. While these incentives vary between SSDI and the Supplemental Security Income (SSI) Program, Melissa learns that the key one for her under SSDI would be IRWE. Under the IRWE provision, Melissa can set aside her earnings for the purchase of work-related equipment or for meeting other work-related goals. By use of IRWE, the income set-aside is not taken into account in determining her countable earnings, so Melissa will be able to remain under the income ceiling, at least for a while.

However straightforward this all may be in principle, practical difficulties immediately begin to emerge. Because earnings are calculated on a monthly basis, Melissa faces the problem created by the way her earnings are received. In some months she

receives no payments at all, while in others, depending on when contract milestones are achieved or when client's fiscal departments happen to pay invoices, her income seems quite large. Averaged out, it is exactly what she expected and exactly what SSA expects, but the number of months required to reach the mean can vary.

As a result, several times Melissa has been threatened with benefit cutoff (which would occur after a three-month grace period following the determination of her ability to work) due to her earnings. She has managed, but only at considerable emotional, temporal, and monetary cost, to have these adverse determinations reversed. The experience has left her shaken, however, and not entirely unwilling to consider concealment of earnings or funds for what she regards as highly regrettable but necessary reasons.

Melissa never before has been mistrustful of government, especially of a benefit programs such as Social Security, but despite having avoided economic ruin, the experience has left her guarded and suspicious. The costs of this attitude, to her and to the effective administration of the public programs in question, are impossible to quantify, but they are eminently real and significant.

Despite recurring accounting problems due to timing discrepancies, Melissa perseveres. Her business grows slowly, as do her savings, which eventually will be put toward fulfillment of her professional potential. Melissa learns of a business incubator in her area (i.e., a business development center or business locator), but because her business is home based she learns she is not eligible for its services and cannot readily utilize its resources. One benefit for which she would be eligible is participation in a local IDA Program. This would offer an alternative means for sheltering and accruing needed funds. Perhaps another option would involve another way, if she had earnings that exceeded the SGA level and that did not necessarily need to be put toward the AT. But far from being an alternative or adjunct capital accumulation mechanism, for Melissa the IDA proves to be no savings mechanism at all, because the goals of the local IDA Program, consistent with the governing federal statute, include business start-up or establishment, but do not clearly allow business expansion. Melissa seeks guidance on

this but cannot get the authoritative guarantees that her now perhaps overly cautious nature has caused her to need. She is left with IRWE.

As important as Melissa's SSDI has been her Medicare. Though she joins an association of small businesses, she is unable to obtain any sort of private coverage that would come close to meeting her needs. Accordingly, retention of Medicare will be a key concern even should her income continue to rise. It now has become difficult to justify enough of a set-aside of funds to meet work-related needs. She still requires some new access equipment, but she can afford it out of her earnings and still will be left with income that exceeds the SGA amount.

As she faces a periodic and continuing disability review (of her eligibility), Melissa searches for some way to decouple her Medicare from her SSDI cash payments. She learns that several mechanisms indeed exist for doing this, and that even if her Medicare were to be curtailed it would be possible to reinstate both it and cash benefits on an expedited basis in certain cases, using the extended period of eligibility provisions of the law. But any interruption of coverage is simply too risky.

The best solution seems to come out of the Ticket to Work and Work Incentives Improvement Act. Melissa learns that SSDI recipients participating in the Ticket Program ultimately can retain Medicare coverage for as long as eight and a half years. But this avenue, too, seems blocked to her, for she cannot find a suitable employment network to accept her "ticket." First, she is neither employed nor seeking employment, but already gainfully, if fragilely, self-employed. The local ENs want to help people get jobs. Second, due to deterioration of her functional capabilities (i.e., health), the service she most needs through the EN is further help with environmental-control equipment (ECU), including equipment to facilitate alternative methods of accessing her computer system. SSA has questioned the strict work-relatedness (and hence the income excludability) of this equipment, characterizing it as a personal expense instead. SSA's position in this regard derives further momentum from IRS's recent determination, in an audit of her prior year's return, that some of the equipment costs Melissa claimed as business expenses should have been treated as medical expenses.

In any event, the ECU would cost more than the EN's anticipated profit from cashing Melissa's ticket under either of the available ticket payment systems. Accordingly, as appears to be their prerogative within the law, they all decline to work with her.

Melissa now finds that she could obtain a catastrophic care policy. Utilizing a health savings account (HSA), the exorbitant costs of even this coverage could be brought down to a net figure that would be barely tolerable, but catastrophic costs are not her immediate concern. Rather, it is the routine costs of the specialized services and the continuity she needs that are the issue. Neither Medicare nor any other known source would allow her to avail herself of catastrophic care coverage. Fearful that the next SSA eligibility review will result in a determination that she is capable of engaging in SGA, based partly on her productivity and partly on her income, Melissa reluctantly concludes that her only safe course of action is to scale back her business and reduce her income below the SGA level.

At Melissa's next SSA continuing eligibility review, she is suspected of manipulating her earnings in order to remain eligible. She successfully refutes this allegation, continues working productively but at a far lower level than she would like or indeed than she is capable of working, but she keeps her health insurance. Melissa is no quitter. She is a survivor in every sense of the word, but the system has forced her to make choices that, in the aggregate, appear to make no sense from any policy point of view. Worse yet, they are not even conscious choices made by society after coherent deliberation. They are the accidental consequences of multiple program interactions and input lacking any mechanism for taking one another into account.

Case Study 2: Application of the POWER Framework to Melissa's Situation

Life for Melissa under the POWER proposal would of course be quite different. Following her accident, her entitlement to any federal income support in the nature of SSDI and any medical insurance in the form of Medicare would depend on some assessment of the related variables of medical condition and present ability to make a living. For purposes of the POWER framework proposal, the nature of the initial

eligibility assessments would not need to change. Strategies identified in the POWER framework focus on what is involved in the retention or subsequent loss of benefits, especially for people like Melissa who acquire disabilities after periods of time in the workforce.

So far as her return to productivity and her self-sufficiency are concerned, the question is the same as is confronted in all work-incentives analyses: Do the nature, extent, and rate of benefit loss correlate effectively with the acquisition of economic and social resources needed to replace the benefits? In Melissa's case, as the "before POWER" scenario has shown, again, that they do not correlate.

Applying Strategy A – Entitlement Policy

Melissa has encountered three recurrent problems. The basic problem, which will not be discussed here because it is ubiquitous, is that of overwhelming legal and administrative complexity. That problem can be solved by simplifying the rules and procedures to enhance the interest in and use of specific work incentives. Each layer of reform that has been imposed on the SSDI system going back to 1981 has been undermined to some degree by the additional burdens of complexity, implementation inconsistency, and overall uncertainty that have been added to the decision process for program administrators and recipients alike. Essentially, suspending the application of means testing for five years (once a few simple, easily understood, and readily knowable conditions are met) cuts through the complexity to the maximum degree possible. NCD recommends suspension of means testing for only five years. Thus, initially the changes are limited to an experimental population and expose the government and the taxpayers to limited, indeed to minimal, financial risk during the time its benefits and implications are being studied.

Applying Strategy B – Element B3, Medical Expense

Turning to Melissa's individual problems, two remain. One is universal. This is the loss, threatened loss, or feared loss of health insurance coverage (in this case, Medicare)

under circumstances where the combination of ongoing medical need plus the unavailability of alternative private coverage makes this risk unsustainable.

Once again, a POWER proposal cuts through this problem by offering a simple guarantee of the continuation of Medicare for five years. This guarantee is subject to Medicare's continued availability, possibly as a buy-in pursuant to the payment of a reasonable income-based premium thereafter (and without the complexities associated with current provisions allowing its retention for a potential eight and a half years under the Ticket to Work Act).

Melissa's final problem is the most specific to her personal circumstances. The twofold problem is at once the most easily resolved and the most intractable of the issues facing her in returning to productivity through gainful work. She is a person who to some degree has skill and a potential to develop a small business, and she can to some degree decide on the rate at which that business grows. Yet, the Social Security Administration, not alone among major programs, is poorly aligned, if not ill disposed, to maximize her ability to do this at the rate she sees fit.

Her first problem was how to amass the capital needed to start her small business without being deemed to have income suggestive of the ability to work, or without risking being found capable of engaging in SGA. The five-year grace period would solve this problem and eliminate this worry. Her acquisition and use of capital for developing her small business would be irrelevant, as would be the rate at which her business expands and the levels of taxable income it yields. Continuing disability reviews likewise would not take place, and the moratorium on them currently contained in the ticket should be applied.

Melissa's second Social Security-specific problem was that the rules governing IRWE and other work incentives and income/resource-sheltering opportunities were crafted to enable her to start her business but not to grow it, or not to grow it to a point where she could sustain herself without benefits. Recall that once her income was sufficient that deduction of the cost of work-related expenses no longer brought that income below the

SGA level, Melissa found herself in a vicious bind. Every expansion of her business, every additional dollar of profit, exposed her to greater risk. The loss of benefits would leave her in a financially perilous position long before her business had ramped up sufficiently to equalize the harm.

Applying Strategy B – Tax Policy Element B2

Here, too, POWER offers a simple solution premised on the assumption that if left free of such risks for five years, Melissa will be in a position such that all benefits can be scaled down and eliminated. The result should be long-term savings to the public.

One other area of concern here relates to tax law. Although POWER includes changes to the tax law, discussion has not included the disproportionately burdensome effects of current law upon Melissa's prospects. Under current law, a number of the business tax benefits that small businesses utilize would not be available to her, while the value of some others, though technically available to her, would be lost.

With respect to business tax benefits that would be unavailable, Melissa, though her business has fewer than 15 full-time employees (it has just one), would not be allowed to claim the Disabled Access Credit, unless part of her home were used exclusively for meetings with clients or customers. Melissa does not have clients come to her home. She conducts her negotiations, meetings, and site reviews via the Internet.

Without going into the intricacies of why the IRS has restricted application of the tax credit on behalf of small firms with fewer than 15 employees, it is enough to note that were the tax credit available to Melissa, it could greatly facilitate her ability to acquire the equipment she needs to grow her fledgling enterprise. That is good for everyone, even for her competitors, if one believes in the discipline of competition in the free marketplace.

Other provisions such as the Architectural/Transportation Tax Deduction (barrier removal) also are unavailable for technical reasons stemming from their out-of-date

premises. Any serious governmentwide effort to return people with disabilities to the mainstream economy will need to confront these issues. POWER addresses the issues in detail.

Ambiguities in the treatment of certain medical or business expenses present further problems. In one scenario, Melissa's costs for ECU technology for use in her home business were denied tax deductibility as business expenses. This ruling is plausible, albeit bad policy, under current law. But it is equally possible that a different auditor could, under current law, have denied Melissa even a medical deduction for her ECU and other access expenses. Moreover, even where a personal deduction is allowed, its value may be severely limited if the cost was met out of savings rather than out of current earnings, because an itemized deduction is available only against current income. For someone like Melissa, who was not necessarily relying totally on current income, and for someone who was starting or growing a small business with loan capital, the problem would be the same. The POWER framework also offers Melissa the benefits of expanded eligibility for IRWE to nonitemizers and a change in the threshold trigger to be able to utilize the Medical Expense Deduction with a corresponding definition of coverage that includes other disability-related expenses such as assistive technology.

An emerging new tax issue relates to the role of the New Markets Tax Credit. Specifically, it relates to the means available to link small businesses owned and staffed by people with disabilities, particularly home-based businesses in targeted communities, to the benefits of the law. Under POWER, Melissa might benefit from location of her business in such an empowerment zone.

In conclusion, the premise undergirding Melissa's scenarios, before and after POWER, is that the expenditure of potentially additive public funds over the short term will yield long-term savings in program costs as well as other measurable benefits to society. Even if these measures cannot be proved in advance to result in these benefits, their actual cost relative to projected benefit is sufficiently small under the demonstration program model as to make the risk well worth taking.

Case Study 3: Parents Raising a Child with Significant Disabilities: James, a Teenager

Robert and Jill Robbins live in Hampton Roads, Virginia, with their three children. Their oldest child, James, who at the start of this scenario is 16 years old, was born prematurely and has multiple physical and intellectual challenges. Through persistence and advocacy, James's parents have been successful in negotiations with their local school system. The result has been that James attends his neighborhood school and participates in regular classes with students without disabilities with the support of an aide whose duties include helping James use a communication device. James and his parents are involved in secondary school transition planning for postschool adult living.

Based on family assets and income, James is not eligible for SSI benefits or Medicaid. The Robbinses estimate that extra costs of health care, including purchase of assistive technology items that were not included in James's Individual Education Program (IEP) through the school system, are in excess of \$12,000 annually. The health care and assistive technology costs also were beyond the scope of group coverage provided through Mr. Robbins's employer. The Robbinses started 529 Plan accounts for their two other children to plan ahead for college education. However, as part of his involvement in IEP team transition planning, James has indicated that he would like to work after high school. With input from James about his preferences and interests, the parents' postsecondary expectations are that his school training and transition planning have prepared him to find employment after he ages out (at age 22) of public education under the provisions of IDEA. Based on the level of their son's functional assistance needs, as middle-aged parents who are primary caregivers, the Robbinses also are concerned about where James will live, how he will maintain a personal assistant for daily living activities (including morning preparations for travel to a workplace), and who will be responsible for helping him with a number of other matters after they are deceased.

Mr. and Mrs. Robbins would like to set aside funds for James for his adult years but are worried that any assets will count against him in determining eligibility for SSI and Medicaid and other public benefits when James is an adult. From friends, they have

heard that it is not a reasonable expectation for James to work and become self-sufficient. Other families explained to the Robbins family that they also should be concerned about possible loss of health benefits and disincentives to employment and asset building inherent in means-tested public benefits. Yet, consistent with their son's communications to them, the Robbinses persist in their belief that someday James will be a business owner and home owner. Struggling with the extra costs of raising a child with significant disabilities, there are millions of families like the Robbinses, who are unsure of their child's path to a better economic future in his/her adulthood.

Case Study 3: Application of the POWER Framework to James's Situation

Based in part on the expectations that James will become a contributing member of his community, the Robbins family would benefit from multiple features of the proposed POWER framework. In accordance with amendments to 529 Plans, families with a child who has a significant disability would be allowed to set aside, with favorable tax consequences, funds for purposes other than postsecondary education. The Robbins family will set aside funds in a 529 Plan for James's purchase of assistive technology and the start-up of a business.

The Robbins family also would benefit from changes to the Medical Expense Deduction in two ways. The definition of medical expenses under the POWER framework is clarified to include coverage of the costs for the purchase of assistive technology, home and vehicle modifications, personal assistance services, and respite care in addition to the traditional expenses covered under the Medical Expense Deduction. In addition, the threshold of allowable medical expenses, which currently must exceed 7.5 percent of adjusted gross incomes, would be eliminated. The more broadly defined medical expense and long-term supports deduction would be available regardless of whether the taxpayer itemized deductions.

As soon as James turns 18 years old, he will be eligible for both SSI and Medicaid, and under the POWER framework with the raised resource limits for SSI, he will be encouraged to work and save. The changes to the Medicaid Buy-In would encourage

James to earn more income and save for the start-up of a business and the purchase of a home. Regardless of income level, James would be able to work for five years before being concerned about health benefits.

James also would be encouraged to create a PASS to preserve income and Social Security benefits while setting as a goal to advance his self-sufficiency the start-up of a business and the purchase of his first home. Under the POWER framework, James would not need to create a PASS until after his first five years of work. James also can earn and save without current income and resource limits for the first five years. Disincentives to savings and building assets have been eliminated by applying POWER. James also would benefit from the blending and braiding of funds in an individualized person-centered plan. He also might benefit from careful management of resources in his individual budget that leads to spending less than the allocated amount of funds. In addition, with the application of POWER, James would keep 50 percent of what he saves for his selected asset-building objectives of purchasing, technology, and transportation. Of course, as IDEA requires, throughout all the planning for transition from secondary school to postschool living, the IEP team must involve James and consider his interests and input.

Case Study 4: Moira: Young Adult with a Disability and Not on Public Benefits

Moira is a bright young college graduate seeking employment in the corporate financial analysis field. Although her academic credentials are stellar, she has found that her visual disability has presented obstacles, both expected and unexpected. As a statistician, Moira understands that the effect of the expected obstacles, which may or may not amount to discrimination, is to change the sample size of available employers, reducing the pool of otherwise available and suitable companies through the self-selective exclusion of company representatives who discriminate. But Moira, ever the optimist, knows that many firms remain and that with time and patience she will find a job.

What Moira had not, but perhaps should have, anticipated were the environmental and infrastructural problems confronting her, not only as a job seeker but potentially as a job holder. These are problems of accessible transportation and housing, and of other dimensions of access.

Moira lives downtown, in an area that is reasonably well served by mass transit—a major factor in her choice of location, since she cannot drive. The fact that it is a neighborhood with relatively low rents also was a consideration. Moira reasoned that the web of metropolitan buses converging on the area would assure her of transportation to and from a future work location.

But the county, anxious to spend more money on prison building, and reacting to federal cutbacks, has begun curtailing bus service, reducing schedules on all routes and terminating service entirely on some others. Moira gets a job offer, but under the new bus schedules, it would take her three hours to get to work and three hours to get home, and if any one bus were late by more than six minutes in reaching its transfer point, she would miss the connection and have to add another hour to her trip. Moira attempts to obtain paratransit service but is denied because she is not physically incapable of using mass transit. Moira then tries to find someone with whom she could ride-share or carpool, but no one else at the company lives anywhere near her area, and it would take anyone who picked her up at least a half-hour out of the way. Taking a bus to a meeting point is possible, but the only viable meeting points are in desolate locations, and Moira understandably is afraid. Her own neighborhood's teeming streets are one thing, but desolate areas quite another.

With deep regret, Moira is forced to decline the job offer. Angry, she appeals to the transit agency to restore one particular bus route that would have allowed her to take the job. By leafleting in her neighborhood and along the former bus route, she is able to gather data suggesting that, although the user base for the line was not large, virtually all the people who would use it would be doing so to get to and from work. The transit agency is unimpressed, stating tersely that it is not an employment support program

and that fairness requires that route decisions be based on ridership demand only, not on some assessment of which riders are worthier than others.

Moira uses simple principles to construct a chart showing that, by dividing the cost of the mass transit service by the number of jobs made possible or saved, taking into consideration the taxes generated by the workers and other factors, the economy would benefit by reinstating the service. But the mayor and city council indicate they have no control over the transit agency, which is an independent authority.

Despite her low rent, Moira believes that, from the asset accumulation standpoint, she would be better off as a home owner. Fortunately, she receives a small inheritance that is just enough to make a down payment on a suitable home. Finding one in the leafy suburbs proves problematic, again because of transportation reasons, but eventually she finds one that is seven blocks from a monorail station. The only trouble is that to get there she has to cross a new kind of traffic circle that is extremely dangerous because of uninterrupted vehicle traffic flow.

Moira petitions the local government to install lights or certain other technology that would make the crossing safer. Claiming to have no money and no legal obligation, the government refuses her request, instead offering to put up a humiliating sign on the curb warning motorists: DRIVE SLOWLY, BLIND PERSON NEARBY. Moira declines the offer. Her research discloses that federal law and state traffic or building codes do not purport to cover this situation, although requirements bear upon major new projects paid in whole or in part with federal funds. On behalf of all pedestrians, elders, and people with various disabilities, she appeals to the voters, running for City Council on a person-friendly platform. Unfortunately, Moira is defeated and moves back downtown.

At length, Moira finds another house in a new development. Its control features, including heating, cooling, kitchen appliances, cable-readiness, and so forth, are all hardwired. All are inaccessible, utilizing flat-panel, digital controls that cannot be accessed by a person lacking vision—indeed, by a person lacking vision and motor skills and good coordination between them. It is all the latest in high tech, but it would

cost upwards of \$20,000 to tear out and replace, and Moira just does not have that much extra money, especially since she now is living on her small inheritance while looking for a job.

Finally Moira finds a job. Joyously, eagerly, she begins work, after a one-and-a-half-hour bus trip, but problems arise because the firm's local area network is not fully compatible with the screen-reader software she uses, and because the company utilizes spreadsheets and other graphic materials that screen-readers cannot access. While readers can be hired to help access them, the productivity losses cannot be made up easily. The firm says that it would investigate systematic retrofitting of the information technology system if tax subsidies were available. Moira finds that the Disabled Access Credit, which would be the most obvious subsidy, would not cover the case for technical reasons. The barrier removal deduction is not relevant because all it does is convert capital to ordinary expenses; since this retrofit, unlike building modifications, would be a routine deductible cost anyway, nothing is gained by applying the deduction. However, Moira learns that it does not apply anyway. In the end, because the firm insists on some advantage beyond the mere routine deductibility of the expense—some sort of acceleration or tax credit that does not exist—nothing is done. Moira toils on, below her potential, doing the best she can, doing good work but nothing that on its face would justify the advancement she truly deserves.

Moira hopes for the day when society's institutional arrangements will gain the flexibility to allow her to be the fully engaged and productive person she knows she can be. She has the company of many people in similar circumstances across the country waiting with her.

Case Study 4: Application of the POWER Framework to Moira's Situation

If the POWER framework were introduced, Moira's opportunities and resources to achieve economic self-sufficiency, productive employment, and a higher quality of life would be greatly increased. In particular, a number of the proposals made under Strategy B and Strategy D would prove very valuable. Presently, Moira is not

participating in any public financial or medical assistance programs, so the measures discussed under Strategy A would have no immediate applicability to her situation. The measures in Strategy C will come into play after she secures employment.

Applying Strategy B – Modification to Tax Policy

Because employment seems to be the main issue facing Moira, discussion of the proposed employer tax incentives represents a point of departure. Moira was unable to work at her level of competence, or indeed to achieve the upward mobility of which she was capable, because it was not in her employer's financial interests to invest in the AT she needed. By combining and revising the three employer tax provisions—Disabled Access Credit, barrier removal deduction, and Work Opportunity Tax Credit—the availability of instrumental tax subsidies could be assured. In particular, allowing the Disabled Access Credit for businesses of all sizes, combining the Disabled Access Credit and the barrier removal deduction, and clarifying that a demonstrable purpose to promote accessibility is the criterion for gaining the tax benefit, two key goals could be achieved. All equipment intended for accommodation purposes would be eligible for the benefit, and all firms, whether treating their equipment purchases as capital or ordinary expenses, would receive the benefits of converting the cost into a credit.

It seems likely that under the circumstances described, Moira's employer would be willing to purchase the necessary devices. If not, the changes proposed to IRWE and the Medical Expense Deduction might enable Moira to buy the AT herself. Though her income remains limited, the opportunity to deduct the costs of work-related AT without having to itemize deductions could make the difference. Or, if the deduction is too large to be absorbed by her income for the year, then she could carry the unused portion forward or back to the following or to the preceding year.

Applying Strategy D – Indirect, Community-Based, and Employer Incentives

The POWER framework could have helped Moira get her job. If the Work Opportunity Tax Credit were available for the hiring of all unemployed people with disabilities, not

just people referred by state VR agencies or members of families receiving various forms of government cash payments, Moira and her employer could avail themselves of it.

In connection with Moira's ambition for promotion, the availability of the credit to support upward mobility, through its provision for the first year of work in a new position with the same employer involving a significant increase in salary, would again increase the comfort level for both parties.

While she is primarily focused on employment, Moira's problems reflect the fact that employment cannot be studied in isolation from transportation and housing. Many of the POWER framework proposals would affect these variations of Moira's situation as well. Moira also might benefit from an employer-matched education account to continue to build her skills for career advancement.

Although almost every homeowner in this country is aware of the central role of the tax law in the financial equation of ownership and mortgage, fewer people stop to think about the numerous ways that public money is involved in every phase of the real estate industry. It seems little enough to ask that developers—in return for generous depreciation provisions, tax-favored use of the bonding authority to create investment capital, waiver of local real estate taxes, occasionally even the use of eminent domain to acquire parcels—be expected to incorporate minimal standards of accessibility for all units in single and multifamily developments. The POWER framework incorporates the principles of universal design as a requirement for all publicly subsidized development. Such a requirement should incorporate beneficial accessible design standards for the built environment but also extend to technology access and use that reduces or eliminates barriers to environmental control and communication.

Over time, tax-based and other measures that reward and encourage the building or modifying of housing units in accordance with principles of accessibility will make accessible housing more affordable by increasing supply. Greater choice of location also will follow.

For the time being, Moira's choice of housing is limited, in part by the inaccessibility of fixtures and appliances and by the proximity to public transit. There is little that tax policy can do directly to increase the availability of transit services, but there is much it can do, and indeed has already done, to meet the mobility needs of Moira and other people whose lack of transportation places them at a disadvantage. Under current law, qualified fringe benefits that employers can deduct and that employees can receive tax free include certain transportation-related benefits, such as mass transit subsidies and in some cases free parking. If the disability-related add-on costs of commuting to and from work were similarly treated, or if such costs could be brought within the ambit of the revised Disabled Access Credit, the ability and willingness of employers to provide or help provide alternative arrangements likely would be increased. If, in addition, a share of costs that Moira might pay were deductible under the revised IRWE category (commuting costs currently are not deductible, even if resulting from a disability), then the resources for finding some viable strategy might be at hand.

Taken together, the provisions discussed here would affect Moira's life in ways that are positive for her and beneficial to society and the national economy. All are triggered by work, and all reward employers and employees who demonstrate an entrepreneurial spirit.

4.4. Cost-Benefit Analysis for the Proposed POWER Framework

This report provides estimates of disability and health coverage benefits and tax revenue implications associated with changes in the treatment of disability benefits and other financial incentives designed to encourage people with disabilities to work, to accumulate financial assets, and to attain and maintain financial security for three case scenarios discussed above:

- Case Study 1, concerning a young woman living in Indiana (Mary) who receives SSI and who begins to work for the first time at age 30, at a part-time, minimum-wage job.

- Case Study 2, concerning a middle-aged woman (Melissa) who lives in New York and who, at age 42, is awarded SSDI benefits for a disability acquired through injury.
- Case Study 3, concerning a young man (James) who lives in Virginia and has received SSI benefits since childhood. The scenario introduced him as a 16 year old involved in secondary school transition planning; now, at the age of 22, James has completed his education and is ready to enter the workforce. He takes a minimum-wage job working 30 hours per week.

Before the presentation of estimates, the report describes the methodology, data sources, and underlying assumptions essential to estimates of benefits and tax impacts for each case study.

Methodology

For each case, the calculation included some or all of the following:

- Annual disability benefits (SSI or SSDI)
- Annual health coverage (Medicare or Medicaid) payments made by federal/state government for health services received during the year
- Annual earnings, where applicable³⁷⁰
- Annual federal income taxes paid, where applicable
- Annual FICA contributions (employee and employer)
- Annual employer federal unemployment tax payments
- Annual state income taxes paid
- Annual employer state unemployment tax payments

Annual benefits, earnings, and tax revenues are estimated over a range of years beginning with the start of (or return to) employment and ending at age 64. All benefits, earnings, and tax revenue estimates are calculated in real terms (2007 dollars), with no adjustment for inflation. Benefits, earnings, and tax revenues estimated over the

specified number of years, as required by the analysis, are reported at their present discounted value in 2007. There is no general agreement as to what discount factor should be used, particularly for public policy analysis. The Office of Management and Budget (OMB) recommends a rather conservative discount rate of 7 percent (OMB, 1992)³⁷¹ but also suggests that other discount factors be used as a sensitivity check. The selected discount rates for this study were 4 percent, 7 percent, and 9 percent.

Data Sources and Assumptions

Data to develop these estimates were obtained primarily from those published by the Social Security Administration and Centers for Medicare and Medicaid Services, as well as from other state and Federal Government sources.

Disability Benefits

Annual disability benefits are calculated for each case for each year from the initial case study age to age 65. For SSI recipients, estimates of SSI benefits also are made for the case study subject's remaining lifetime (past age 64). All disability benefits are expressed in real (2007) dollars, with no adjustment for inflation.

SSI benefits for Case Study 1 and Case Study 3 subjects (Mary and James) are set at the 2007 federal monthly benefit of \$623 per individual, and annualized over 12 months. Neither Indiana (state of residence for Case Study 1, Mary) nor Virginia (state of residence for Case Study 3, James) provide an SSI supplement administered by the Social Security Administration to its SSI recipients; eligibility for state-funded supplements in these states is restricted to residents of licensed residential facilities (Indiana) or those in assisted living residences or adult foster care arrangements (Virginia).

SSDI benefits for Case Study 2 (Melissa) are set at \$1,200, with payments beginning in 2007, at a level deemed to be consistent with Mary's work experience and earnings history.

Health Coverage Benefits

Average annual Medicaid benefits for Case Studies 1 and 3 are calculated using state-specific data on mean Medicaid outlays for beneficiaries with disabilities in 2003 from the FY 2006 Medicaid Statistical Information System state summaries maintained by the Centers for Medicare and Medicaid Services. These data are available online at www.cms.hhs.gov/DataCompendium. The July CPI—Consumer Price Index—for medical services (for all urban areas) is used to calculate an average annual reimbursement rate for 2006 (this, of course, assumes that any changes in Medicaid payments are due to price changes only, and not to changes in utilization rates among the Medicaid population of people with disabilities). The assumption is based on actuarial reports (obtained from the *2005 Annual Report of the Boards of Trustees of the Federal Hospital Insurance and Federal Supplementary Medical Insurance Trust Funds*).³⁷² Expense calculations indicate medical service costs increased by 4 percent between 2006 and 2007, to arrive at an average annual Medicaid payment amount of \$17,803 in Indiana and \$13,846 in Virginia per beneficiary with a disability.

Average annual Medicare benefits are calculated using data for aggregate Medicare fee-for-service reimbursements for hospital and SMI—Supplementary Medical Insurance—services paid for the SSDI population, divided by an unduplicated count of SSDI beneficiaries enrolled in either or both of these services. These data were obtained from Table 2.1 (Enrollees) and Table 3.2 (Reimbursements) from the Medicare and Medicaid Statistical Supplements, published by the Centers for Medicare and Medicaid Services, in *Health Care Financing Review* and available online at www.cms.hhs.gov/MedicareMedicaidStatSupp/. Fee-for-service reimbursements are used because fewer than 10 percent of SSDI beneficiaries are enrolled in Medicare managed care plans. Using these data, calculations result in an average annual reimbursement per enrollee for 2004, the most recent date available. The July CPI for medical services (for all urban areas) is used to calculate an average annual reimbursement rate for 2006 (this, of course, assumes that any changes in Medicare reimbursement amounts are due to price changes only, and not to changes in utilization rates among the SSDI Medicare population). The assumption is based on actuarial

reports (obtained from the *2005 Annual Report of the Boards of Trustees of the Federal Hospital Insurance and Federal Supplementary Medical Insurance Trust Funds*), that indicate medical service costs increased by 4 percent between 2006 and 2007, to arrive at an average annual reimbursement amount per SSDI enrollee of \$7,901.

In most instances, the expectation would be that health care expenditures vary with age and other factors over time. However, no models or bases are available for incorporating the impact of age, gender, or specific medical conditions to develop likely Medicare or Medicaid expenditure scenarios for case study subjects. Thus, in this report, average public expenditures on health care for each of the case study subjects, in real terms, stay constant over their remaining work lives.

Life Expectancy

Estimation of lifetime benefits for Case Studies 1 and 3 require some assumption of life expectancy. Estimates provided by SSA, Office of the Chief Actuary (2005),³⁷³ are used. Life expectancy estimates are provided at birth and at age 65. This study elects the conservative approach and uses life expectancies at birth. This is a prudent assumption in light of the fact that what effect, if any, each subject's disability may have on his or her longevity is unknown.

Earnings

For the case study subjects on SSI (Case Studies 1 and 3), the assumption is that these individuals obtain part-time employment initially at the federal minimum hourly wage of \$5.15. These calculations are based on a further assumption that legislation to raise the minimum wage passed by Congress early in 2007 would be signed by President Bush on July 1, 2007. This legislation provides for an increase in the minimum wage to \$7.25 per hour, phased in over a two-year period. Based on the phase-in schedule specified in this legislation, an assumption is that the hourly minimum wage will rise to \$5.85 on September 1, 2007, or 60 days after the legislation is signed into law. One year later

(September 1, 2008), the minimum wage rate increases to \$6.55 per hour; another year later (September 1, 2009), the minimum wage rate increases to \$7.25 per hour.

Once the minimum wage reaches its maximum rate in 2009, the assumption is hourly wage increases for the study subjects, based on anticipated productivity gains.

Productivity gains are estimated using the real-wage differential assumptions (defined as the difference between nominal wage growth and inflation) utilized by the Social Security Administration in its actuarial studies (Social Security Administration, 2005).³⁷⁴ However, deliberations about the anticipated legislation were unresolved as of January 15, 2008, at the time of this publication.

Federal Income Tax

Federal income taxes paid by subjects in Case Studies 1 and 3 are estimates using tax rates effective in 2006, assuming that subjects are single but are not filing as head of household, that they take the standard deduction of \$5,150, and that they each have one exemption (\$3,200). Their only taxable source of income is their earnings³⁷⁵ and the only tax credit that they qualify for is the EITC. Federal income tax payments grow over time as income (earnings) grows.

FICA Taxes

By law, 6.2 percent of all earnings (up to \$97,000 in 2007) comprise the employee's Social Security contribution; another 1.45 percent is withheld from earnings for Medicare. Employers are required to match this contribution. FICA taxes (combined Social Security and Medicare contributions) are calculated at 7.65 percent of earnings for employees. However, the employer's payroll tax contributions (an additional 7.65 percent of earnings paid) reduce taxable business income, which offsets some of the tax revenues generated by this FICA payroll tax.

Federal Unemployment Tax Act

By law (Federal Unemployment Tax Act, or FUTA), employers are required to contribute to the cost of unemployment insurance for workers in their state. This payroll tax amounts to 6.2 percent of all wages paid to their employees (on the first \$7,000 of wages paid).³⁷⁶ However, since most of this contribution is offset by a tax credit on income taxes paid by businesses, the effective unemployment tax rate for most employers is 0.008 percent.

State Income Taxes

Both Indiana and Virginia levy income taxes on their residents. In each state, the starting point for the tax calculation is the adjusted gross income calculated for each of the study subjects. State-specific adjustments to income for exemptions and deductions are required in order to arrive at taxable income. Similar to the federal tax process, calculation for this study used tax rates effective in 2006, assuming that subjects are single, that they take the standard deduction applicable in each state (\$3,000 in Virginia; no standard deduction in Indiana), and that they each have one exemption (\$1,000 in Indiana; \$900 in Virginia). Their only taxable source of income is their earnings,³⁷⁷ and the only tax credit that they qualify for is the state's EITC or its equivalent. State income tax payments grow over time as income (earnings) grows.

State Unemployment Taxes

Employers also contribute to state unemployment insurance funds. State unemployment tax rates can vary with such factors as the number of employees, size of the payroll, and past layoff history (indicating the probability that employees will require unemployment insurance payments in the future). The requirement to pay state unemployment taxes applies to most, but not all, employers in a given state.³⁷⁸

In Indiana, state unemployment tax is charged to the first \$7,000 of earnings for each employee, at a starting rate of 2.7 percent. This rate may be adjusted later, based on the employer's layoff history. For estimation purposes, an assumption is that the study

subject's employer is liable for paying state unemployment taxes and that the employer tax rate is 2.7 percent.

In Virginia, new employers pay 2.5 percent in tax in employee earnings (up to \$7,000 in annual earnings). One year later, the employer becomes eligible for a computed tax rate (ranging from 0 percent to 6.2 percent), based on their layoff history and benefits paid to laid-off workers. For estimation purposes, the application is made of a state unemployment tax rate of 2.5 percent to the first \$7,000 of earnings reported for the Case Study 3 subject in each year of his employment.

Benefits, Earnings, and Tax Revenue Estimates

The estimated benefits, earnings, and tax revenue impacts associated with earnings are provided below for the three case studies. For each case, the estimate includes the following:

- Total benefits (disability and health coverage benefits) that would be paid out over the remaining benefit life of the case study subject. For Case Studies 1 and 3, which involved SSI benefits, the remaining benefit life is estimated in two parts:
 - The remaining work life of the subject through age 64
 - The postretirement years, defined as age 65 through the subject's expected life expectancy
- For Case Study 2, an SSDI recipient, the remaining benefit life is defined as the subject's work life.
 1. Total benefits paid under Scenario 1, where disability benefits cease five years into the subject's remaining work life. Disability benefits would cease immediately after five years, while health coverage benefits would transition out based on current extended health care coverage provisions (extended period of eligibility for Medicare benefits and continued Medicaid coverage under Section 1619[b]).

2. Total benefits savings under Scenario 1. For the SSDI recipient in Case Study 2, this estimate is simply total benefits paid out over the remaining work life (Scenario 1) minus total benefits paid for five years only (Scenario 2). For SSI recipients, total SSI benefits paid out over remaining work life only (Scenario 1a) as the baseline for measurement of benefit savings.
3. Total benefits paid under Scenario 2, where disability benefits remain in place for the first five years into the case study subject's life and are then phased out over the next five years. This phase-out of disability benefits proceeds as follows:
 - Year 6: Receive 70 percent benefits
 - Year 7: Receive 45 percent benefits
 - Year 8: Receive 25 percent benefits
 - Year 9: Receive 15 percent benefits
 - Year 10: Receive 10 percent benefitsHealth coverage benefits continue into the future, based on current regulations extending health care coverage for Medicare and Medicaid beneficiaries who work.
4. Total benefits savings under Scenario 2, calculated as (1) minus (4) for Case Study 2 and (1a) minus (4) for SSI recipients.

For Case Studies 1 and 3, which address SSI beneficiaries and workforce entry, the estimated earnings are calculated over the remaining work lives of the subjects and the estimated federal and state taxes that will be collected from these earnings.

Case Study 1 (Earnings and Tax Estimates)

The case study involves Mary, a 30-year-old woman with a disability who lives in Indiana and who has never worked. She receives Supplemental Security Income payments at the federally mandated monthly rate of \$623 in 2007, and is eligible for

Medicaid coverage. She takes a part-time job at the current federal minimum wage of \$5.15 per hour, and works 25 hours per week. For estimation purposes, an assumption is made that this employment position continues until she reaches age 65. Mary's life expectancy, given that she was born in 1976, is about 77 years.

Table 2 provides estimates of SSI and Medicaid benefits that Mary will receive over her estimated life span of 77 years. Total remaining lifetime SSI benefits for Mary, discounted back to 2007 using a 4 percent discount rate, are \$158,455. Of these, \$139,537 are benefits that would be paid out over her remaining work life (that is, up through age 64); the remaining \$18,918 is the present discounted value (at 4 percent) of the SSI benefits that would be paid to her at age 65 through age 77. Associated Medicaid benefits are \$388,681 over her entire remaining lifetime, with \$332,286 associated with her remaining work life and \$56,395 estimated as benefits that she would receive postretirement. Similar interpretations apply to SSI and Medicaid benefits estimates discounted at 7 percent and 9 percent.

Estimates of benefits impacts and savings over Mary's working life under two alternative benefits scenarios are presented in table 3. If Mary were to receive her SSI benefits for only five years (2007 through 2011), she would receive only \$33,282 in SSI benefits (expressed at their present value discounted at 4 percent). Thus, the benefits savings under this scenario, defined as total working lifetime SSI benefits (\$139,537) less five years of benefits (\$33,282) is \$106,255. Note the use of work life benefits, rather than total lifetime benefits, as baseline here. This reflects the underlying premise of this scenario that the continuation of SSI benefits for five years after the onset of employment will enable Mary to work steadily from age 30 through age 64, thus building up credit toward Social Security Old-Age and Survivors Insurance (OASI) benefits. These OASI benefits will provide some offset to SSI benefits savings. At the same time, if these benefits are not very low, Mary still may qualify for SSI benefits. The net benefits picture postretirement is not clear-cut. In this study, the use of work life as the baseline for benefits scenarios provides a conservative estimate of SSI benefits savings for Mary.

Likewise, extending SSI benefits for more than five years after employment, with a gradual phase-down between years 6 and 10, results in a total of \$42,633 in SSI benefits paid out. This results in lifetime SSI benefits savings of \$96,904 (the difference between total work life SSI benefits of \$139,537 and the \$42,633 in benefits paid out under Scenario 2). Note that there is no change in Medicaid benefits paid out under either Scenario 1 or Scenario 2. While Mary is working and is not receiving SSI benefits, her earnings never exceed her state's 2007 earnings threshold for Medicaid benefits under Section 1619(b).

Earnings and tax revenues generated as a result of continued employment until age 65 are provided in table 4. The present value of Mary's lifetime earnings from age 30 through age 64, discounted at 4 percent, is \$194,155. She will pay \$1,278 in federal income taxes over her work life and \$5,813 in state income taxes. Her employment will generate a total of \$29,706 in FICA revenues; 50 percent of these are paid by her employer and 50 percent are paid by Mary. Her employer also will pay a total of \$8,100 in federal unemployment taxes and \$3,528 in state unemployment taxes over the course of her employment—all values expressed in terms of their present discounted value (4 percent). Total federal tax revenues generated by her employment total \$39,804, while state tax revenues total \$9,341. Her post-tax earnings, which exclude her portion of all tax revenues generated by her employment, come to \$172,058 (discounted at 4 percent). Table 4 provides analogous earnings and tax revenue estimates for discount rates of 7 percent and 9 percent.

Finally, the assumption is that Mary's SSI benefits end after five years of employment (that is, under Case Study 1, Scenario 1). Assuming a 4 percent discount rate, it would take six years beyond this initial five-year period to accrue sufficient SSI benefits savings to match SSI benefits expenditures during the first five years. Comparable time periods using 7 percent and 9 percent discount rates are eight years and nine years, respectively.³⁷⁹

TABLE 2: LIFETIME SSI AND MEDICAID COSTS: CASE STUDY 1 (Mary)
(2007 Dollars)

	Discount Rate: 4 percent			Discount Rate: 7 percent			Discount Rate: 9 percent		
	SSI	Medicaid	Total	SSI	Medicaid	Total	SSI	Medicaid	Total
Total benefits ages 30–77*	158,455	388,681	547,136	102,649	250,766	353,415	81,730	198,522	280,262
Total benefits paid during work life (ages 30–64)	139,537	332,286	471,823	96,797	230,507	327,304	78,998	188,121	267,119
Total benefits paid in retirement (ages 65–77)	18,918	56,394	75,312	5,852	20,259	26,111	2,742	10,401	13,143

*Mary's assumed life expectancy is 77.

TABLE 3: WORK LIFE SSI AND MEDICAID COSTS AND SAVINGS: CASE STUDY 1 (Mary)
(2007 Dollars)

	Discount Rate: 4 percent			Discount Rate: 7 percent			Discount Rate: 9 percent		
		Medicaid	Total	SSI	Medicaid	Total	SSI	Medicaid	Total
Total benefits ages 30–64	139,537	332,286	471,823	96,797	230,507	327,304	78,998	188,121	267,110
Scenario 1: Benefits SSI	33,282	332,286	365,568	30,653	230,507	261,160	29,079	188,121	217,200
Scenario 1: Lifetime benefits savings	106,255	0	106,255	66,144	0	66,144	49,919	0	49,919
Scenario 2: Benefits paid	42,633	332,286	374,919	38,313	230,507	268,820	35,810	188,121	223,931
Scenario 2: Lifetime benefits savings	96,904	0	96,904	58,484	0	58,484	43,188	0	43,188

Scenario 1: SSI benefits paid over first five years only. Medicaid extended until remaining work life, as earnings never meet the Section 1619(b) threshold. Scenario 2: SSI benefits phased out over second five years. Medicaid extended until remaining work life, as earnings never meet the Section 619(b) threshold.

**TABLE 4: EARNINGS AND TAX PAYMENT ESTIMATES: CASE STUDY 1 (Mary)
(2007 dollars)**

	4 percent	7 percent	9 percent
Total lifetime earnings (ages 30–64 years)	194,155	129,998	103,876
Federal tax revenues attributable to earnings			
Federal personal income tax revenues	1,278	140	(237)
FICA taxes paid (by employer and employee)	29,706	19,890	15,893
FUTA taxes paid (by employer)	8,100	5,619	4,586
Total federal tax revenues*	39,804	25,649	20,242
State tax revenues attributable to earnings			
State income tax revenues	5,813	3,854	3,060
State unemployment taxes paid (by employer)	3,528	2,447	1,997
Total state tax revenues*	9,341	6,301	5,057
Total federal and state revenues generated*	49,145	31,950	25,299
Total post-tax earnings	172,058	115,933	92,997

*Does not include possible business income tax revenue offset attributable to higher payroll tax expenses.

Case Study 2 (Earnings and Tax Estimates)

Melissa is a 42-year-old woman who has sustained a disabling injury and has qualified for SSDI. Table 5 presents estimates of benefits savings (SSDI and Medicare) associated with two benefits scenarios in this NCD study.

If she remains on the SSDI rolls until she reaches age 65, when she presumably would be eligible for Social Security retirement benefits, her total SSDI benefits would come to \$208,169, discounted at 4 percent. Her associated health coverage benefits under Medicare total \$114,218.

Of these total lifetime SSDI benefits, \$58,337 are received in the first five years. If SSDI benefits ceased after five years due to earnings in excess of the substantial gainful activity level, Medicare benefits would continue for an additional 8.5 years. Thus, Medicare benefits under Scenario 1 include a total of 13.5 years of benefits, or \$78,012 (discounted at 4 percent). If SSDI benefits were to cease after five years, total lifetime SSDI benefits savings would amount to \$149,832, and Medicare benefits savings would total \$36,206.

Similarly, if SSDI benefits are phased out between the sixth and tenth years, SSDI benefits paid out over 10 years are estimated at \$76,349; Medicare benefits over 18.5 years would total \$98,731. This phase-out of SSDI benefits, with its associated impact on Medicare eligibility, would provide benefits savings of \$131,821 in SSDI benefits and \$15,488 in Medicare benefits, both discounted at 4 percent. Similar estimates using discount rates of 7 percent and 9 percent are also provided in table 5.

**TABLE 5: LIFETIME SSDI AND MEDICARE COSTS AND SAVINGS: CASE STUDY 2 (Melissa)
(2007 Dollars)**

	Discount Rate: 4 percent			Discount Rate: 7 percent			Discount Rate: 9 percent		
	SSDI	Medicare	Total	SSDI	Medicare	Total	SSDI	Medicare	Total
Total benefits ages 42–64	208,169	114,218	322,388	156,712	85,985	242,697	132,450	72,673	205,123
Scenario 1: Benefits paid	58,337	78,012	136,349	53,435	64,489	117,925	50,506	57,316	107,822
Scenario 1: Lifetime benefits savings	149,832	36,206	186,038	103,277	21,496	124,772	81,944	15,357	97,301
Scenario 2: Benefits paid	76,349	98,731	175,080	68,190	77,492	145,682	63,471	66,926	130,397
Scenario 2: Lifetime benefits savings	131,821	15,488	147,308	88,522	8,492	97,015	68,979	5,747	74,726

Scenario 1: SSDI benefits paid over first five years only. Medicare extended for 8.5 years thereafter.

Scenario 2: SSDI benefits phased out over second five years. Medicare extended for 8.5 years beginning in year 11.

Case Study 3 (Earnings, Benefits, and Tax Estimates)

This case study focuses on James—introduced at age 16 who has received SSI payments since turning 18 and now, at age 22, is ready to enter the workforce. James currently receives the federally mandated minimum SSI payment of \$623 per month, with no state supplement. James now lives in Virginia and begins working 30 hours per week at a minimum-wage job. As in Case Study 1, the assumption is that James works continually in this type of position until he reaches retirement age. James's life expectancy, given that he was born in 1985, is 70 years.

In table 6 are estimates of SSI and Medicaid benefits reveal what James could receive over his estimated life span of 70 years. Total remaining lifetime SSI benefits for James, discounted back to 2007 using a 4 percent discount rate, are \$159,549. Of these, \$152,292 are benefits that would be paid out over his remaining work life; the remaining \$7,257 is the present discounted value (at 4 percent) of the SSI benefits that would be paid to James between age 65 and age 70. Associated Medicaid benefits are \$295,494 over his entire remaining lifetime, with \$282,054 associated with his remaining work life and \$13,440 estimated as postretirement Medicaid benefits. Similar estimates are provided for discount rates of 7 percent and 9 percent.

Estimates of benefits impact and savings over James's working life under the two alternative benefits scenarios are presented in table 7. If James were to receive SSI benefits for only five years (2007 through 2011), he would receive \$33,282 in SSI benefits (expressed at their present value discounted at 4 percent). Thus, the benefits savings under this scenario, defined as total working lifetime SSI benefits (\$152,292) less five years of benefits (\$33,282) is \$119,010. Again, in application of POWER, work life benefits used, rather than total lifetime benefits, are the baseline here.

Likewise, extending SSI benefits for more than five years after employment, with a gradual phase-down between years 6 and 10, results in a total of \$42,633 in SSI benefits paid out. This results in lifetime SSI benefits savings of \$96,904 (the difference between total work life SSI benefits of \$139,537 and the \$42,633 in benefits paid out

under Scenario 2). As with Case Study 1, there is no change in Medicaid benefits paid out under either Scenario 1 or Scenario 2.

Earnings and tax revenues generated as a result of continued employment until age 65 are provided in table 8. The present value of James's lifetime earnings from age 30 through age 64, discounted at 4 percent, is \$236,897. He will pay \$6,967 in federal income taxes over his work life and \$6,313 in state income taxes. His employment will generate a total of \$36,246 in FICA revenues; 50 percent of these are paid by the employer and 50 percent are paid by James. His employer also will pay a total of \$8,206 in federal unemployment taxes and \$3,565 in state unemployment taxes over the course of his employment; all values expressed in terms of their present discounted value (4 percent). Total federal tax revenues generated by his employment total \$51,419, while state tax revenues total \$9,897. James's post-tax earnings, which exclude his portion of all tax revenues generated by his employment, come to \$226,841 (discounted at 4 percent). Earnings and tax revenue estimates for discount rates of 7 percent and 9 percent also are provided in table 7.

TABLE 6: LIFETIME SSI AND MEDICAID COSTS: CASE STUDY 3 (James)
(2007 Dollars)

	Discount Rate: 4 percent			Discount Rate: 7 percent			Discount Rate: 9 percent		
	SSI	Medicaid	Total	SSI	Medicaid	Total	SSI	Medicaid	Total
Total benefits ages 22–70*	159,549	295,494	455,043	102,921	190,615	293,536	81,849	151,589	233,438
Total benefits paid during work life ages 22–64	152,292	282,054	434,346	100,978	187,017	287,995	81,025	150,062	231,087
Total benefits paid in retirement ages 65–70	7,257	13,440	20,697	1,943	3,598	5,541	824	1,527	2,351

*James's assumed life expectancy is 70 years.

**TABLE 7: WORK LIFE SSI AND MEDICAID COSTS AND SAVINGS: CASE STUDY 3 (James)
(2007 Dollars)**

	Discount Rate: 4 percent			Discount Rate: 7 percent			Discount Rate: 9 percent		
	SSI	Medicaid	Total	SSI	Medicaid	Total	SSI	Medicaid	Total
Total benefits ages 22–64 years	152,292	282,054	434,346	100,978	187,017	287,995	81,025	150,062	231,087
Scenario 1: Benefits paid	33,282	282,054	315,336	30,653	187,017	217,670	29,079	150,062	179,141
Scenario 1: Lifetime benefits savings	119,010	0	119,010	70,325	0	70,325	51,946	0	51,946
Scenario 2: Benefits paid	42,633	282,054	324,587	38,313	187,017	225,330	35,810	150,062	185,872
Scenario 2: Lifetime benefits savings	109,659	0	109,659	62,665	0	62,665	45,215	0	45,215

Scenario 1: SSI benefits paid over first five years only. Medicaid extended over remaining work life, as earnings never meet the Section 1619(b) threshold. Scenario 2: SSI benefits phased out over second five years. Medicaid extended over remaining work life, as earnings never meet the Section 1619(b) threshold.

**TABLE 8: EARNINGS AND TAX PAYMENT ESTIMATES: CASE STUDY 3 (James)
(2007 Dollars)**

	Discount Rate		
	4 percent	7 percent	9 percent
Total lifetime earnings (ages 22–64)	236,897	157,402	120,372
Federal tax revenues attributable to earnings			
Federal personal income tax revenues	6,967	4,046	2,925
FICA taxes paid (by employer and employee)	36,246	24,083	19,182
FUTA taxes paid (by employer)	8,206	5,657	4,606
Total federal tax revenues*	51,419	33,786	26,713
State tax revenues attributable to earnings			
State income tax revenues	6,313	3,749	2,815
State unemployment taxes paid (by employer)	3,565	2,364	1,897
Total state tax revenues*	9,878	6,113	4,712
Total federal and state revenues generated*	61,297	39,899	31,425
Total post-tax earnings	226,841	143,914	113,337

*Does not include possible business income tax revenue offset attributable to higher payroll tax expenses.

Case Study 4: How to Monetize Policy/Program Impacts for Assessment Purposes

Cost-benefit analysis provides a framework for identifying, organizing, measuring, and comparing the costs and benefits, broadly defined, of any proposed regulation, policy, or program. The primary question that this analysis seeks to answer is: Do the aggregate benefits to be achieved equal or exceed all costs associated with a new/altered regulation or policy? Properly done, cost-benefit analyses consider all costs and benefits, with some recognition that costs and benefits are not evenly distributed across various stakeholders in society. Aggregation of all benefits and all costs for comparison purposes requires the ability to measure these costs and benefits in monetary terms. However, intangible impacts, or costs and benefits that cannot be easily measured in monetary terms, also should be recognized and reported. Additionally, not all costs and benefits accrue to stakeholders who are affected directly by the proposed regulation, program, or policy; third parties also may be affected, positively or negatively. These indirect costs and benefits also should be measured and considered.

For more than 25 years, the Federal Government actively has espoused the use of some comparative analysis of costs and benefits to assess new regulatory initiatives³⁸⁰ and, somewhat more recently, to assess the impact of policy or programmatic changes in health and welfare programs. The following methodologies and tools are examined briefly to explore their efficacy when applied to disability-related issues.

Use of Cost-Benefit Analysis in the Regulatory Arena: Environmental Regulation

The Environmental Protection Agency uses cost-benefit analyses when considering new regulations or when periodically reviewing existing regulations. To assess and measure benefits associated with implementing a more stringent air quality standard for a specific pollutant, analysts typically rely on existing studies that allow some estimation of the impact of the change in air quality on some outcome.

A relatively straightforward application of this process can be used to assess agricultural (crop) impacts associated with changes in air quality. There is a broad range of plant pathology studies, conducted in carefully controlled laboratory conditions, that provide detailed dose-response information on how specific types of plants respond when exposed to a specified air pollutant at a specified level. These dose-response functions can be applied on a grander scale to predict the expected increase or decrease in yields for specific crops under alternative ambient air quality standards. Applying these dose-response functions to area-specific data on acreage planted with each type of crop, and valuing projected changes in crop yields at market prices, will provide monetary estimates of the impact of changing regulations on the agricultural sector.

Note that this measurement of the potential benefits associated with increasingly stringent air quality standards begins with a scientific, laboratory-based measurement of how the outcomes (crop yields) are likely to respond to a change in ambient air quality. A straightforward approach is available for valuing these changes, using market-established prices. The benefit associated with improved air quality—higher crop yields—also is well defined. Assessing the impact of changes in air quality on people is not as easy.

One might expect that improved air quality (resulting from more stringent ambient air quality standards) would result in better health among the population, measured as fewer deaths from respiratory-related causes and lower incidence/prevalence of acute or chronic respiratory conditions. To assess the impact of a change in air quality standards (or to compare the relative effects of a range of standards) on human mortality and morbidity (both acute and chronic), the investigator could look for epidemiological studies that would allow investigators to measure the (quantifiable) health effects associated with changes in air quality. To be useful for replication, these studies would have to produce a plausible dose-response curve or function that could be applied to the alternative air quality standards under consideration. In other words, the investigator would need to use results from existing studies to predict, for a given

increase/reduction in an air quality standard, the likely decrease/increase in mortality and morbidity rates associated with that change.

These impacts must then be assigned a dollar value. This can be done in various ways. Increases or decreases in pollution-related deaths can be valued using statistical value of life measures or other measures. Morbidity effects can be valued as increases or decreases in direct medical expenditures, work loss days, and reduced activity days. Work loss days and reduced activity days also must be assigned a monetary value, typically reflecting prevailing average wages (or some portion thereof for a reduced activity day). Census data can be used to extrapolate these impacts to county or other local-level populations, and these smaller-area estimates can be combined for a national estimate.

This brief summary about the use of epidemiological studies to assess benefits associated with changes in air quality standards and regulations hides a multitude of difficulties. It would be a rare event indeed to find an epidemiological study that is perfectly suited, in methodological and technical terms, to the task at hand. The scope and breadth of the cost-benefit analysis is limited to the specific types of health effects measured in these studies; there may well be other effects for which no suitable prior studies exist. There also may be other personal benefits to cleaner air, including reduced soiling/cleaning expenses and aesthetic benefits; these are not captured by these epidemiological studies (although there may be other evidence to support estimates of these benefits).

The economic literature can provide an alternative approach to measuring benefits for improvements in air quality by measuring the willingness to pay (WTP) for this environmental amenity. Early, crude WTP studies (using hedonic wage and hedonic property value models) postulated that local differences in average wage levels or in property values reflected, in part, differences in air quality that could be measured as the ambient levels of specific air pollutants. The portion of the wage or property value differential attributable to differential exposures to a specific pollutant could be used to measure willingness to pay to avoid this exposure. Once again, this estimate can be

extrapolated over the entire population, building up from area-specific estimates, to arrive at a national estimate. This approach, conceptually, includes all the perceived benefits associated with cleaner air; however, it is not clear that WTP measures can adequately measure all benefits. While there have been further developments in approaches to conceptualizing and measuring WTP over the last 20 years, information has not been made available regarding their application to environmental regulation.

The comments in the report concentrate on applications of cost-benefit analysis to environmental regulation to measurement of benefits, based on limited experience. Cost estimates typically are developed from an engineering basis, looking at specific sources of pollution and determining what equipment or other costs would be incurred to bring emissions from each source into compliance with more stringent emissions standards. Engineers sometimes use a narrow concept of costs, compared to economists, who look at the impact of (and possible costs and benefits associated with) changes. For example, changes in plant production process and for the global market, changes in possible standards would be very difficult to measure, and would require a highly stylized and simplified conceptual model with some loss of “real world” conditions.

The EPA can utilize cost-benefit analysis in its regulatory decision process because there exists some scientific basis in vetted and published academic research, however imperfect, for measuring the impact of changes in air quality standards on some important outcomes. The proposed changes in air quality standards also do not attempt to elicit changes in human behavior, and do not require such changes among the population at large for their successful implementation. The situation is different when one considers policies or regulations that directly affect human behavior or that are designed to influence human behavior in some way.

Application of Cost-Benefit Analyses to Disability Policy Initiatives

Using cost-benefit analysis to assess proposed disability policy initiatives is no easy task. First, in contrast to the example of the use of cost-benefit analyses in setting or evaluation of air quality standards, there is little, if any, hard research that directly

measures or documents how the target population (people with disabilities) will react or be affected by the implementation of specific policy initiatives. For example, suppose that implementation occurs during a transition period where SSI or SSDI benefits are maintained or phased out rather than entirely cut off once earnings eligibility levels are exceeded. Will this motivate and assist people with disabilities to seek employment and develop earnings capacity that will enable them to sustain themselves in the long run without receipt of disability benefits? No data or studies are available to answer this question, quantify the impacts, and conduct a cost-benefit analysis.

Another example reports a fair amount of evidence (from survey statistics and from anecdotal sources) that the lack of accessible transportation is a barrier to employment for at least some people with disabilities. But much remains unknown about this population. How many people with disabilities are affected? What are their specific transportation needs (which will vary depending on type or severity of disability, geographic location, employment location and work days/hours, and the availability of accessible transit options)? What types of transportation solutions would help at least some of these people obtain and sustain gainful employment? Would the gains to individuals and society as a result of a specific transportation solution equal or exceed the costs of that solution to implement and maintain? Some interesting insights may be gained by looking at evaluations of recent federally funded initiatives to address the needs of a range of transportation-disadvantaged groups, including people with disabilities, but only if program data can identify users with a disability. Data or studies to answer the questions posed above were unavailable for this report.

In general, if existing studies or data could be used to construct a valid cost-benefit analysis for programs or policies that address social needs or attempt to induce some sort of behavioral change for the population with disabilities, the situation would be considered highly unusual. The definition and measurement of this target population is hampered by a lack of consistency across existing studies in how disability is defined. And certainly the identification of what constitutes disability can and should change, depending on the policy issues under consideration. But this remains a key

methodological barrier that impedes any attempt to contrast, compare, and possibly generalize from findings across existing studies that purport to examine the same behavior or answer the same questions.

More to the point, there are no scientifically reviewed, methodologically valid studies or other empirical evidence available from which costs and benefits can be extrapolated for most policy prescriptions and programs relevant to disability issues. There are good and compelling reasons for this. To assess the economic impacts of policies that seek to influence individual behavior and decisions, there is need to observe and measure the behavioral response to these policies. Methodologically sound cost-benefit analyses in the social policy arena require significant time and resources to conduct; it also can take years to observe the complete impact. The experience of the welfare reform experiments conducted between late 1980s and the mid-1990s can provide some lessons here.

Section 1115 of the Social Security Act allows the secretary of Health and Human Services to waive specific provisions of this act within individual states for the purpose of implementing and charting the effectiveness of these waivered program elements and policies. During the 1980s, the Federal Government encouraged states to use this waiver process to develop and test new initiatives at the state level to reduce the number of recipients of Aid to Families with Dependent Children (AFDC), ease the transition into the labor market for AFDC recipients, and otherwise improve the lives of AFDC recipients and their families. Between 1987 and 1996, HHS approved 83 waiver applications. Each of these approvals required a rigorous analysis of the costs, benefits, and impacts of the waivered program elements, and typically imposed a specific methodology for conducting this evaluation. The costs of these evaluations were borne by the Federal Government.

The methodology of choice for most of these evaluations was an experimental design in which welfare recipients were selected at random and placed into two groups. One group, the experimental group, would be treated under the new (waivered) welfare program or rules. The other group, the control group, would not be subject to the new

rules; the old rules would apply to this group. Differences in measurable outcomes (such as employment, earnings, educational attainment, and other programmatic objectives) could be attributable to programmatic differences. Differential costs and benefits in program elements and administrative costs could be calculated and compared as well. Nonexperimental methods (typically pre- or post-analyses of time series data) were approved in a few cases where state officials argued that an experimental design was not appropriate or not feasible.

The use of experimental methods in social policy research is more easily described than implemented. In the context of the welfare reform experiments described above, it typically was very difficult to implement and maintain control conditions for the very small number of welfare recipients who were selected at random to be treated under the former program rules and regulations. These experiments also were designed typically to extend over several years (the typical evaluation had a five-year time frame) to allow sufficient time for clients to complete job training and other program requirements and for behavioral impacts to materialize and be observed. This long time frame added to the costs of these evaluations. This also is a long time in terms of the political process. Policymakers and political interests typically want answers more quickly, particularly when an election beckons. For example, New Jersey was the first state to implement a family cap provision in its welfare program, in October 1992. By the following summer, in the heat of a gubernatorial election campaign and before the federally mandated program evaluation began, the state released statistics purportedly showing a decline in births among women on welfare. The family cap clearly was working, only 10 months after it went into effect!

Lessons for Application of Cost-Benefit Analysis to Disability Issues

A cost-benefit analysis for any proposed policy or program cannot be done without methodologically valid empirical evidence on how the target population for that policy or program is affected. This evidence is just not available for policies and programmatic proposals that attempt to address barriers to employment and quality of life for people with disabilities. However, past history indicates that if an issue matters to the Federal

Government (as was the case with welfare reform), the Federal Government is willing to invest significant funds into economic evaluations of various policy proposals.

Design and implementation of methodologically sound studies to measure the impacts, costs, and benefits of proposed policies to assist people with disabilities is no easy task, and the identified issues only scratch the surface regarding what should be addressed. But it is clear that specific studies must be designed and initiated to gather and analyze impacts, costs, and benefits of specific disability policy proposals. These studies must use appropriate methodologies. Perhaps small-scale studies or studies that are confined to a specific location or subject to other restrictions can be designed, which can then be generalized to broader populations of interest. The study design should ensure that all material costs and benefits (direct and indirect, and tangible and intangible) are covered, and a sufficient time must be allowed to observe a behavioral response to the program or policy.

Chapter 5: Summary of Findings and Recommendations

This report creates a four-part conceptual framework POWER, based on the research findings from the first three chapters, to set a clear direction for supporting increased economic status for people with disabilities. Real-life case studies and a cost-benefit analysis applying the POWER framework depict how a combination of strategies might modify existing public policies. The proposed actions can enhance indirect, community-based, and employer incentives to provide a comprehensive blueprint for change.

The POWER framework also recognizes the complexity and scope of changes needed to secure the full benefits of encouraging work, income preservation, and asset building for individuals with disabilities and their families. The range of legislative amendments for consideration will affect tax policy and the entitlement authorities under Social Security and Medicaid, in addition to the federal tax code, including the existing tax incentives to employers and asset-building provisions.

In the four changes proposed to Social Security and Medicaid, access to health care would continue for five years regardless of new income levels to reduce disincentives to work and asset building. The changes to Social Security rules would offer multiple options to encourage income preservation and asset growth. Recommended changes include the following:

1. Raise resource limits for SSI to \$20,000 and index it annually for inflation thereafter with no loss of benefits for five years of working at or above SGA.
2. Enact an earnings offset for SSDI beneficiaries that parallels the work incentives for SSI.
3. Modify income and resource limits through simplified Medicaid Buy-In that allows work and access to health care for five years, regardless of income level.

4. Expand PASS to allow for savings for home ownership or any asset-building goal, including the purchase of assets that will generate income in later years.

In addition, the proposed revisions to the tax code include four changes that will help people with disabilities and their families level the playing field of community participation. The proposed tax code changes support work outcomes and allow tax considerations of costs associated with living with a disability; the changes also call for improvements in the existing tax incentives to employers. Such changes would consolidate and expand code provisions to encourage hiring and accommodating workers with disabilities. Another proposed change involving a modified 529 Plan would allow and encourage families to save to benefit their children with disabilities who may not go on to higher education but have other asset-building goals.

1. Bundle and revise Business Tax Credits for more efficiency and use (Disabled Access Credit, Architectural/Transportation Tax Deduction, and Work Opportunity Tax Credit).
2. Revise the IRWE exemption so that it applies to any reasonable expense incurred for the purpose of employment.
3. Revise Medical Expense Deduction threshold requirements and waive the need for deductibility.
4. Amend 529 Plans created exclusively for families with children going onto higher education to include purposes and goals that meet the needs of families with children who have disabilities.

The POWER framework's proposed focus on savings and asset building through amendments to the Assets for Independence Act involve expanding and refining opportunities for people with disabilities through IDAs and Medicaid-funded Individuals' Budgets. The POWER framework also recognizes the importance of financial literacy to

understand and use credit effectively and manage a budget. These critical skills should be taught in grades K–12 and continue to be developed for adults with disabilities.

1. Expand and refine IDAs to meet the needs of people with disabilities.
 - a. Include transportation and technology as a purpose for saving.
 - b. Provide incentives to encourage private match to federal funds.
 - c. Allow private and state-authorized and state-funded IDAs to adopt federal IDA rules, which exclude counting the resources for purposes of continued eligibility for public benefits.
 - d. Require financial education to be conducted in accessible locations with accessible content and be accessible online.
2. Encourage financial education as part of an individual's education and work plans: IEPs, Transition Plans, Plans for Employment through VR, and the Workforce System.
3. Simplify implementation of individual budgets.
 - a. Invite SSA, the Department of Education and its Rehabilitation Services Administration, the departments of Education and Labor, CMS, and SAMHSA to collaborate in the development of a cross-agency template that simplifies the implementation of unified individual budgets that promote self-determination and person-centered plans for adult living.
 - b. Allow savings and asset-building rewards that permit an individual to keep 50 percent of what he or she does not spend in an individual budget. The savings must relate to a specific asset-building objective in an individualized plan.

The last part of the POWER proposals for change focuses on indirect financial incentives made available through an employer or a housing developer. The five areas affected are as follows:

1. Housing Design Standards
 - a. HUD should adopt universal design standards developed by the Access Board.
 - b. HUD should require that the adoption of universal design standards become a conditional requirement for any entity that receives HUD financing for single or multifamily dwellings.
2. Qualified Allocation Plan Set-aside for 20 Percent of Units: All units receiving LIHTCs should adopt new universal design standards and reserve 20 percent of units to be affordable to individuals with disabilities who are at or below 30 percent of AMI.
3. New Markets Tax Credit: Require each federally funded project that is creating jobs to document job creation, outreach and recruitment efforts, and the number of people with disabilities hired.
4. Employer Transportation and Housing Deductions: Allow a tax deduction to employers for the costs of assisting employees with disabilities with the costs of transportation and first-time home ownership.
5. Employer-Matched Education Accounts: Allow employees who contribute up to \$500 to an education and training account to receive a tax credit for their deposit. Allow an equal match from their employer that would be deducted from corporate income taxes. Individuals must earn less than \$25,000 to be eligible for the benefit.

This report concludes with a brief review of the key findings and recommendations for action by essential Administration, congressional, and federal agency leaders.

5.1. Summary of Key Findings on Financial Incentives

1. Financial incentives are complex without consensus on definition, and need explanations about various types such as disability-based, cash and in-kind, direct, indirect, or community-based funding streams.

2. Financial incentives are underutilized.
3. Individuals with and without disabilities are denied the opportunity for savings and asset growth because of the means testing to remain eligible for many public benefits.
4. Low-income wage earners do not benefit from many federal tax provisions that promote savings and asset development.
5. Direct, indirect, and third-party financial incentives have an important impact on people with disabilities and their families.
6. There are no one-size-fits-all financial incentives strategies.
7. Financial incentives funding strategies are interrelated.
8. Opportunities for low-income individuals with disabilities that encourage and support savings and asset acquisition are limited and need to be expanded.
9. Disability remains an all-or-nothing proposition based on eligibility determination and disability definition.
10. Several financial incentives need modification to provide parity for people with disabilities (i.e., making opportunities available comparable to those available to their peers without disabilities).
11. A consensus model is unavailable for evaluating the impact of financial incentives.
12. Gateway costs of living with a disability are more expensive than costs of living without a disability.
13. Disability programs are heavily weighted toward the use of resources for determination of status and assessment of eligibility.

14. The conversion of federal financial disincentives to incentives is possible.
15. Public accounting practices, especially the practices related to federal savings across programs and services, need review.
16. Definite cost benefits are found when the framework and strategies introduced in this report are applied to three of the case studies presented.
17. Cost benefits for Case Study 4 are unknown because scientifically reviewed, methodologically valid studies for this purpose are lacking.

5.2 Summary of Major Recommendations According to Federal Leadership

For the Administration:

Recommendation 1 – NCD calls for an Executive order that identifies actions for federal agencies, including the following:

Department of Health and Human Services/Office of Disability and the Centers for Medicare and Medicaid Services

Department of Labor

Department of Housing and Urban Development

Department of Transportation

Department of Education

Department of the Treasury

Social Security Administration

The Administration should create a federal interagency workgroup on financial incentives for people with disabilities and their families; develop an Executive order calling for all agencies to identify policy barriers; and create a time-limited body to facilitate a consistent, coordinated, comprehensive, and consumer-friendly approach to advance opportunities for full community participation and economic self-sufficiency.

For Congress:

Recommendation 2 – NCD proposes actions by the Senate Finance Committee, House Ways and Means Committee, and House Energy and Commerce Committee. Congress should introduce and consider adoption of the POWER framework set forth in this report. It should accomplish the work by making appropriate changes in federal legislation pertaining to Social Security, Medicaid, savings, asset building, and the relevant aspects of the federal tax code.

For Federal Agencies:

Recommendation 3 – NCD advises that NIDRR take the lead and work in partnership with other federal agencies to raise the level of awareness about financial incentives and people with disabilities and their families. In preparation, the following lead agencies for implementation should consider how to refocus their evidence-based research efforts to include financial incentives.

Department of Education, Office of Special Education and Rehabilitative Services/NIDRR

Department of Health and Human Services, Centers for Medicare and Medicaid Services/Assistant Secretary for Planning and Evaluation

Social Security Administration

Expand the volume of and access to knowledge about the cost-benefit outcomes of direct and indirect financial incentives that advance self-sufficiency for people with

disabilities, including the establishment of a new financial incentives Rehabilitation Research and Training Center to add to the sparse knowledge base.

Recommendation 4 – NCD identifies actions needed to increase awareness and utilization of the financial incentives and benefits supported by federal funding.

In partnership, the following key federal agencies need to fund collaborative/interagency demonstration projects aimed to improve capacity for employer and community use of financial incentives and to advance tangible economic impact; examine the affects of applying selected financial incentives with attention to support through tax credits, affordable and accessible housing, transportation, continuing education, and related life essentials; and include this work in all agency performance plans and annual reports to Congress.

Department of Housing and Urban Development

Department of Commerce

Department of Education

Department of Transportation

Department of the Treasury

Internal Revenue Service

Recommendation 5 – NCD recommends that the federal agencies identified below expand and improve financial education opportunities and outreach to children and adults with disabilities across economic levels and types of abilities.

Federal Deposit Insurance Corporation

Internal Revenue Service

Department of Labor

Department of Education

Social Security Administration

Through the use of direct and indirect financial incentives, federal agencies can have a key role in advancing real economic impact. A consumer-friendly education and information effort needs to apprise low-income workers with disabilities about their potential eligibility for financial incentives such as the Earned Income Tax Credit. SSA, the Department of Labor, and the Department of Education should engage in work to support opportunities for improving the skills linked to empowerment, income maintenance, and asset building among people with disabilities.

Appendix: Mission of the National Council on Disability

Overview and Purpose

The National Council on Disability (NCD) is an independent federal agency with 15 members appointed by the President of the United States and confirmed by the U.S. Senate. The purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities regardless of the nature or significance of the disability and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

Specific Duties

The current statutory mandate of NCD includes the following:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act, as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities, to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.
- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities in the Federal Government, at the state and local government levels, and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on individuals with disabilities, access to health care, and policies that act as disincentives for individuals to seek and retain employment.

- Making recommendations to the President, Congress, the Secretary of Education, the director of the National Institute on Disability and Rehabilitation Research, and other officials of federal agencies about ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.
- Providing Congress, on a continuing basis, with advice, recommendations, legislative proposals, and any additional information that NCD or Congress deems appropriate.
- Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (ADA) (42 U.S.C. § 12101 et seq.).
- Advising the President, Congress, the commissioner of the Rehabilitation Services Administration, the assistant secretary for Special Education and Rehabilitative Services within the Department of Education, and the director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.
- Providing advice to the commissioner of the Rehabilitation Services Administration with respect to the policies and conduct of the administration.
- Making recommendations to the director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting people with disabilities.
- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this council for legislative and administrative changes to ensure that such recommendations are consistent with NCD's purpose of promoting the full integration, independence, and productivity of individuals with disabilities.
- Preparing and submitting to the President and Congress an annual report titled *National Disability Policy: A Progress Report*.

International

In 1995, NCD was designated by the Department of State to be the U.S. government's official contact point for disability issues. Specifically, NCD interacts with the special rapporteur of the United Nations Commission for Social Development on disability matters.

Consumers Served and Current Activities

Although many government agencies deal with issues and programs affecting people with disabilities, NCD is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, veteran status, or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of people with disabilities and eliminating barriers to their active participation in community and family life.

NCD plays a major role in developing disability policy in America. In fact, NCD originally proposed what eventually became ADA. NCD's present list of key issues includes education, transportation, emergency preparedness, international disability rights, employment, foster youth with disabilities, vocational rehabilitation, livable communities, and crime victims with disabilities.

Statutory History

NCD was established in 1978 as an advisory board within the Department of Education (P.L. 95-602). The Rehabilitation Act Amendments of 1984 (P.L. 98-221) transformed NCD into an independent agency.

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³⁷¹ OMB. (October 29, 1992). *Guidelines and Discount Rates for Benefit-Cost Analysis of Federal Programs*. (Circular No. A-94 Revised, Transmittal Memo No. 64). Washington, DC.

³⁷² HHS, CMS. (March 23, 2005). *2005 Annual Report of the Boards of Trustees of the Federal Hospital Insurance and Federal Supplementary Medical Insurance Trust Funds*. Rockville, MD. <http://www.cms.hhs.gov/ReportsTrustFunds/>

³⁷³ SSA, Office of the Chief Actuary. (2004, September). *Unisex life expectations at birth and age 65*. Baltimore, MD. (Actuarial Note No. 2004.2).

³⁷⁴ SSA , Office of the Chief Actuary. (2005) Actuarial Study No. 119: *Short-range actuarial projections of the old-age, survivors, and disability insurance program*. SSA. Baltimore, MD.

³⁷⁵ Their only other source of income, SSI, is not taxable.

³⁷⁶ However, we note that a tax credit on income taxes paid by businesses offsets much of this contribution.

³⁷⁷ Their only other source of income, SSI, is not taxable.

³⁷⁸ As is the case with other payroll taxes, there is likely some federal and state tax revenue offset associated with these high payroll expenses.

³⁷⁹ These same time frames will apply in Case Study 3.

³⁸⁰ See Executive Order 12291, Federal Regulation (1981, February 17); and Executive Order 12866, Regulatory Planning and Review (1993, September 30).